

Person-Centered Approach to Nursing Practice
in a Heart Function Clinic: An Integrative Literature Review

Susan J. Kerr RN, BSN, BSc

A project submitted in partial fulfillment of the requirements for the degree of Masters in
Nursing in the School of Nursing, Faculty of Human and Social Development,
University of Victoria

Supervisor: Dr. Lynne Young RN, PhD, Professor, School of Nursing

Committee Member: Lenora Marcellus, RN, PhD, Associate Professor, School of Nursing

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Dedication

TO MY MOM AND DAD

for raising me to believe anything was possible

AND TO MY HUSBAND

for making everything possible

Acknowledgements

“Those who overcome great challenges will be changed, and often in unexpected ways. For our struggles enter our lives as unwelcome guests, but they bring valuable gifts. And once the pain subsides, the gifts remain. These gifts are life's true treasures, bought at great price, but cannot be acquired in any other way.” ~ Steve Goodier

I would like to extend my gratitude to my supervisor, Dr. Lynne Young, committee member, Dr. Lenora Marcellus and my editor, Audrey McClellan, for their patience and support during this project. Their expertise and insights provided me with both personal and professional growth in ways I could not have imagined.

To all the people who have shared their experiences of living with heart failure through their powerful stories, I thank you. To my friends and colleagues, you supported me on this emotional roller coaster. You celebrated my successes and held me up when I was down.

To my mentors, I am blessed to have crossed paths with you. Your generous gifts of experience, knowledge, and perspective have provided me with sustenance during this journey and have forever changed me.

To my mom, Margaret, and brother, Adrian Popple, I am grateful for your generous and unconditional love and support. To my dad, James Popple (1927–1986), you live on in my thoughts and memories. During times of struggle, I was reminded how he, too, worked on his Masters while working full-time. History will repeat itself as my daughter will graduate from high school as I graduate with my Masters, just as I graduated from high school the year my dad completed his second Masters.

To my daughter, Jordan, and my son, Aidan Kerr, thank you for your loving understanding throughout this educational adventure. May you have the confidence to fulfill your dreams. You will always have my endless love and support as you venture forward in life.

Finally, to my husband, Steven Kerr, you lovingly cared for Jordan, Aidan, and me since we came into your life. You nourished us with food and with your love during my journey. You were my warmth in the cold, my sunshine in the rain. You helped me laugh when I had lost my sense of humour. You never gave up on me; instead, you provided me with hope. You have given me greater love and joy than I could have imagined. Now that this project has come to fruition, it is my time to be there for you.

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Abstract

The management of heart failure (HF) is complex, both for those experiencing HF and for those caring for people in an outpatient setting such as a Heart Function Clinic (HFC). Since the Institute of Medicine (IOM) (2001) identified patient-centered care as an essential foundation for quality and patient safety, much has been written about this type of care; however, it is not a new approach to nursing. In order to synthesize published literature examining the relationship between a person-centered care approach and the self-management of people living with HF, an integrative literature review was undertaken. Appropriate articles published between January 2001 and June 2014 were identified using CINAHL, Medline, Cochrane Database of Systematic Reviews, and Google Scholar. People present along their journey to self-management at different stages, which are related to certain life challenges that can affect an individual's ability to adjust to living with HF. Supported by nursing theory and competency tools, such as the heart failure competency assessment, planning, and evaluation (HF-CAPE) tool, the nursing approach at each stage varies to support the person living with HF and their family. Following an integrative review of HF self-care literature with a person-centered care approach, the data were reduced until five themes were identified. These themes are (1) communication, (2) fostering understanding, (3) encouraging problem-solving, (4) sharing decision-making, and (5) setting person-defined goals. While the overarching theme of *communication, including building of relationships*, underpins the other four themes, the remaining themes are not mutually exclusive; they are interconnected but not in a linear fashion.

Key words: *person-centered care approach, heart failure, self-management, outpatient care*

A patient arrives at a Heart Function Clinic in a city in the province of British Columbia. He is asked for his provincial health card as he checks in at the desk and is then directed to a waiting room that is filled with people. When the nurse comes to get him, he is taken to a room and the visit begins. It is all business: weight, blood pressure, stand-up, sit down, medications, shouldn't do this, shouldn't do that, any questions—as if the nurse had never met him before and had not asked the same questions on his previous visit. Wait for the doctor. “Why am I here?” the patient thinks to himself.

Another patient arrives at a different Heart Function Clinic, in a different city. She is welcomed by name as she checks in with her health card. The nurse collects her from the waiting room with a smile, and they chat as they reconnect, discussing what has happened since her last time at the clinic. As the visit begins, the nurse asks the patient, “What can I help you with today?” The patient realizes she always feels so supported in her care at the Heart Function Clinic. She is so glad she has somewhere to turn to help her navigate her needs—managing heart failure is not easy.

Part 1: Area of Interest

Background

In 2005, I began my journey as a nurse practicing in a Heart Function Clinic (HFC). It was a new clinic that had opened in the region served by our health authority, and its aim was to help adults living with heart failure (HF) manage their chronic disease in an outpatient setting. Our multidisciplinary team consisted of me, one cardiologist, a clerk, and one exercise specialist with our cardiac rehabilitation exercise program. With our model of care, patients were scheduled to see the nurse and the cardiologist in the clinic at specified intervals; however,

between these visits they were encouraged to phone the nurse with concerns about their health. Some patients called us frequently and some *never* called us.

When we first opened our clinic, our patient numbers were low. Now, ten years later, the Victoria clinic manages over 600 HF patients served by Island Health (VIHA), formerly Vancouver Island Health Authority. To help build this capacity, the team has grown. We still have one cardiologist; however, we have increased the nursing staff to 2.2 full-time equivalents (FTE). Further, the clinic offers more services including social work and psychiatry, and the number of classes in the high-risk cardiac rehabilitation program has increased. An expansion of HF outpatient care in VIHA led to the opening of new HFCs in Nanaimo (2009) and Campbell River (2010) with nursing staff guided by internal medicine physicians. The future vision for the Victoria clinic is to recruit a second HF cardiologist in order to decrease the wait times for HF specialty care within VIHA. As this program continues to grow, we are always looking for ways we, as a team, can provide care for our patients and their family members to help them feel supported and connected along their journey into HF self-management.

From May 2012 to September 2013, I co-formed and led a provincial working group of HFC nurses to develop a practice resource that outlined standardized competencies for registered nurses (RNs) practicing in HFCs in British Columbia (BC). This practice resource is called the heart failure competency assessment, planning, and evaluation (HF-CAPE) tool (Provincial Heart Failure Network, 2013a). Development of the framework for the practice tool was guided by the College of Registered Nurses of British Columbia's (CRNBC) professional standards (2012) and Patricia Benner's (2001) novice to expert theory. Embedded within the HF-CAPE tool are standardized evidence-based learning resources to support the specialized body of knowledge required for nurses practicing in our provincial HFCs.

The competencies in the HF-CAPE tool were developed by nursing experts looking through the lens of a nurse new to HF practice. As I reflected on this tool, I wondered whether it adequately explicated the concept of *patient-centered care*. Health care providers talk about providing patient-centered care all the time, but clear parameters of this concept are undefined in all practice areas. How does an advanced practice nurse (APN) lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC? Before describing how I approached this question, I will provide some background on HF and HFCs, and discuss the definition and concept of patient-centered care, particularly as it relates to nursing.

A Review of Heart Failure

Heart failure causes significant mortality and morbidity in Canada (Arnold et al., 2006). Over 100,000 residents of BC have HF (BC Ministry of Health, 2013). This represents an annual cost of over \$500 million to the provincial health care system making it the most expensive chronic disease in BC (Cardiac Services BC, 2010). Mortality depends on various factors including the severity of symptoms, heart dysfunction, and age (Ross et al., 2006). The progression of HF can vary. For most people who suffer from HF, periods of relative stability of cardiac functioning will be interspersed with exacerbations of disturbing symptoms—some of which will require the person to be hospitalized. Each episode of acute onset of symptoms brings a further decline in a person's functional capacity even after the symptoms have improved. The challenging journey of managing HF creates a dualism of *living well with HF*, as the time between each acute onset of HF symptoms narrows until the *end of the person's life* (Penrod, Hupcey, Baney, & Loeb, 2011).

From a physiological perspective, HF is not a disease—it is a complex syndrome that results from the inability of the heart muscle to move blood effectively throughout the body. The heart *fails* to meet the body's needs for oxygen. There is no cure for HF and it does get progressively worse over time; however, treatment can relieve symptoms and slow the gradual worsening of the condition. Approximately half of all cases of HF are caused by a previous heart attack or disease in the coronary arteries. Other causes of HF may include high blood pressure, heart valve problems, sleep apnea, viruses that affect the heart, certain types of chemotherapy, genetics, heart rhythm problems, and excessive use of alcohol or drugs. Sometimes the cause is not clear.

Regardless of the *cause* of HF, there are similarities in the *treatment* people undergo for this condition—some of the goals of the treatment are to treat the underlying cause of the HF when possible; provide evidence-based medications to relieve symptoms, slow the progression of the disease, reduce the need for emergency room visits and hospitalization, and help people live longer; and provide education about lifestyle changes to enable people with HF to manage the condition and its symptoms.

The majority of people living with HF are managed by primary care physicians (PCPs) and nurse practitioners (NPs) in their community. Elderly people with HF often experience comorbidities that include chronic ischemic heart disease, atrial fibrillation and flutter, depression, diabetes, renal failure, hypertension, and chronic obstructive pulmonary disease (Dai et al., 2012; Lossnitzer et al., 2013) that may require repeated hospitalization and a higher level of care than can be provided by PCPs and NPs. For this reason, the care of people living with HF can become complex and resource intensive, and frequently requires access to care and alternative resources within the health care system that are offered at an HFC.

Heart Function Clinics

A Heart Function Clinic is an outpatient service delivered by a multidisciplinary team of health care professionals, frequently led by APNs, to support the self-management of patients and their families living with the challenges of HF. These specialty clinics give high-risk people access to HF specialists who provide investigations, optimal medical management, monitoring, and education to decrease mortality and hospitalizations through the use of evidence-based therapies and practices (Ross et al., 2006). However, less than five percent of all people living with HF are referred to these specialty clinics.

HFCs in BC vary in size, but most offer physician-guided, nurse-led models of care. Some clinics are nurse-led in partnership with GPs; some in collaboration with a cardiologist or an internist. The larger clinics in the province have a full multidisciplinary team with more than one cardiologist, several RNs, an NP, a clinical nurse specialist (CNS), a social worker, a psychiatrist, a psychologist, a pharmacist, a dietitian, an exercise specialist, and several clerical staff.

Heart Failure Self-Management Support

One way nurses foster the optimum health of people living with HF is by supporting self-management. *Self-management* refers to an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition such as HF (Glasgow, Davis, Funnell & Beck, 2003). Self-management is an active process, and the *self-care behaviours* asked of people with HF to maintain their stability and prevent worsening symptoms include taking medications as prescribed, limiting fluid intake, limiting dietary sodium intake, weighing themselves every day, monitoring for

worsening HF symptoms, and recognizing when it is time to seek assistance from a health care professional (Stromberg et al., 2003; Arnold et al., 2006).

However, self-management support is not as simple as providing didactic education about these self-care behaviours and then hoping to see positive outcomes in people living with HF. Barriers along the journey to self-management can be related to persons, tasks, tools, contexts, or the interaction of several of these components (Holden, Schubert & Mickelson, 2015). Even under ideal conditions, the management of these self-care behaviours can be difficult due to the uncertainty of HF. Challenges for people living with HF and their loved ones include lack of knowledge of HF management, an inability to make a connection between changes in certain HF self-care behaviours and HF symptoms, and a lack of experience or confidence to know what to do once symptoms of HF are recognized. Another level of complexity is added to HF management when dealing with other associated characteristics such as impaired memory, attention, and cognitive processing; excessive daytime sleepiness; depression; and impaired family functioning (Riegel, Dickson, Goldberg, & Deatrck, 2007).

The *self-management support* provided in an HFC incorporates collaborative decision-making and goal setting, problem-solving, outreach, and systematic follow-up visits. On a patient's journey toward achieving stability of symptoms, the patient and their family are offered individualized and group education sessions; telephone management between scheduled visits with a physician, NP, or RN; assistance to navigate the health care system with one or more chronic conditions; and consultations and collaboration with various members of the multidisciplinary team.

The health system tends to be physician-dominated and disease-focused, and a specialty clinic, such as an HFC, has the potential to be no different. However, nurses due to their

disciplinary focus on holistic care, envision HFCs that support practices that are person- rather than disease-centered. In the next section I will discuss how the role that nurses play is important to HFCs.

Role of Nursing

While the goals of care for some people include improving survival as a priority, this is not the case for all individuals living with HF; for some, the goal is to live *better*, not *longer*. Their focus of care is not on extending life but, instead, on improving or maintaining functional abilities; reducing signs and symptoms of HF; and, improving or maintaining psychological and social aspects of life. The strength of the findings of van der Kluit, Ros, and Schrijvers (2014) is the ability to redirect the focal point away from the disease process and back to the nurses' domain of *how* HF affects the patient's everyday life. Even though a high proportion of HF randomized-controlled trials (RCT) report patient-relevant outcomes, none reported goal attainment in accordance with persons' individual preferences (Blom et al., 2015). Regardless of what the results of these studies suggest, medical management in the HFC *is* based on the individual's preferences. The role of the nurse is crucial in building relationships with the people living with HF and their family in order to determine the goals of care, which are shared with the multidisciplinary team.

Because of their expertise in clinical practice, APNs are well-positioned to support the complexity of HF in the following ways:

1. *Expert coaching and guidance:* APNs tailor education to the needs of each individual and/or support person; use adult learning principles; and are experts in clinical content.

2. *Consultation:* APNs work with other nurses to meet educational needs in the clinic; they also present case discussions to other nurses and personnel in other disciplines (such as exercise specialists, dietitians, social workers, psychologists, and physicians) to enrich a person-centered approach.
3. *Clinical and professional leadership:* APNs advocate for the patient; act as coordinators of services; and provide a clear commitment to the person living with HF and their family regarding their concerns.
4. *Collaboration:* APNs develop partnerships and involve other health care team members to effect care for the benefit of the person living with HF and their family (Hamric, 2009).

The ability to *quantify* the effectiveness of nursing practice is, often, tied to an intervention. With respect to self-management interventions in nurse-led HF clinics, the traditional disease-specific outcomes of mortality, HF readmission rates, and length of stay (LOS) have been measured to evaluate practice. Nurses provided education and social support to people living with HF and families in a variety of settings including pre-discharge, ambulatory, and hospital- and community-based HFCs. In some studies, the nurses were specially educated and experienced cardiac nurses (Strömberg et al., 2003; Sisk et al., 2006; and van der Kluit, Ros, & Schrijvers, 2014). In others, the nurses received HF education prior to carrying out the intervention (Blue et al., 2001). The combined results of the role of nursing on HF self-management in a nurse-led clinic showed a reduction in HF readmissions to hospital; a reduction in LOS, if readmitted; variability in mortality benefit from increased to none; improvement in self-care behaviours, specifically daily weighing, alerting health care professionals if weight was

gained, and restricting fluid intake; an improvement in functioning; and enhancement of the attention nurses give to a person's everyday life.

Since person-centered care is at the heart of most nursing theories (McCormack & McCance, 2010), nurses are well-situated conceptually to help people living with HF navigate the health care system on their journey from diagnosis through to end of life. Advanced practice nurses, in particular, are grounded in nursing theory, which helps them view the patient through a holistic lens in order to focus on a person-centered approach to care.

Person-Centered Care: A Dominant Discourse in Heart Failure Care

Today there is much talk about providing care that is “patient-centered” or “person-centered,” or delivering care using a “client-centered approach”. Although these terms are in widespread use, they are poorly understood, making the translation of the term into practice challenging. It is easy for the semantic nuances of what are thought of as synonymous terms to be unappreciated if their meanings are not defined and expanded upon. In the following sections I will discuss the definitions and history of the terms client-, patient-, and person-centered care and then focus on person-centered care, especially as it relates to nursing.

Definitions

While the terms *patient-centered*, *client-centered*, and *person-centered care* are used interchangeably and have similar attributes, distinctions can be found as one examines the different philosophical lens used by each approach to care. *Patient-centered care* is associated with the traditional medical model in which the person seeking care is viewed as the sum of biopsychosocial parts, with the emphasis on the physical elements of care (Landers & McCarthy, 2007, p.79). Through this lens, a patient gives up autonomy, placing the doctor in a position of

power. This results in a patient's belief that certain health decisions are best left in the hands of those providing health care. The term *patient* is not restricted to an individual who is ill or seeking health services, but can refer to an individual; a social group, such as a family; or an aggregate, such as members of a community (Lauver et al., 2002, p. 247).

In order to disassociate from the terminology of medicine, the word *patient* is often replaced with *client* to describe one who is the expert on what is best for them. This term is used widely in home and community care (HCC). However, according to Merriam-Webster (2015), *client* refers to "a person who pays a professional person or organization for services"; therefore, the term *client-centered care* is not a good fit in the context of the HFC because involvement with the clinic is covered by the medical services plan of the province.

In contrast to *patient-centered care*, the concept of *person-centered care* rejects a paternalistic view in which the doctor holds all the power. Instead, its guiding principle is the premise that people should not be reduced to their disease alone (Leplege et al., 2007). It conceptualizes the *person* from a humanistic perspective that takes into account what makes us uniquely human and recognizes a person's innate right to be autonomous (McCormack, 2003). Being person-centered requires the formation of therapeutic relationships between professionals, patients, and their family, and these relationships are built on mutual trust, understanding, and sharing collective knowledge (McCormack & McCance, 2006, p.473). While the semantics of these terms differ, there are similarities in foundational attributes that ground these approaches to care, which will be discussed in the next section.

Classical Perspective

In 1957, American psychiatrist Carl R. Rogers presented his theory of therapy, personality, and interpersonal relationships, as developed in the client-centered framework

(Rogers, 2007). Rogers wondered if it was possible to identify conditions that were both *necessary* and *sufficient* to bring about constructive personality change in psychotherapy. He believed if six conditions were present over a period of time, the process of change would follow. The first condition identified was that a *relationship* must exist between the therapist and the client. The next five conditions defined the *character* of the relationship, which included the *client's vulnerability* and *perception of the therapist*, and the *therapist's genuineness*, *unconditional positive regard*, and *empathy*. Although initially presented for the fields of psychotherapy and counselling, Rogers suggested that this theory also had implications for other fields, such as training for leadership in industry and the military; programs aiming to develop character and personality as well as intellectual skills; and community agencies working to produce personality and behavioural change in delinquents and criminals (Rogers, 2007).

Certain aspects of Rogers' theoretical framework were ahead of their time. First, Rogers' concept of a *way of relating or being* as opposed to a *way of doing* was in stark contrast to the then current medical model. Second, Rogers' assumption that *unconditional acceptance* of the client would naturally bring about the desired change was in contrast to the standard method of actively trying to change the client. Finally, his belief that an accurate psychological diagnosis of the client was *not* necessary for a psychotherapist to experience empathy and full acceptance, and be an effective therapist, flew in the face of standard practice (Elliott & Freire, 2007, p. 286).

Realm of Medicine

The ground breaking components of Rogers' client-centered theory were eventually translated to other professional fields, including medicine. Because psychotherapists' patients were usually referred to as "clients," and medical doctors usually saw "patients," the term *patient-centered care* was used. In 1993, a book entitled *Through the Patient's Eye* (Gerteis,

Edgman-Levitan, Daley, & Delbanco) introduced seven dimensions of patient-centered care. Researchers from Harvard Medical School used focus groups made up of recently discharged patients, family members, physicians, and non-physician hospital staff to develop these dimensions which included respect for patients' values, preferences, and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity.

The notion of patient-centered care was unique for its time in medicine. It was recognized as an aim of health care delivery when the Institute of Medicine's (IOM) report *Crossing the Quality Chasm* (2001) discussed the work of Gerteis et al. and identified patient-centered care as an essential foundation for quality and patient safety. The IOM was concerned that the health care system lacked consistent, high-quality medical care for all patients because of the growing complexity of health care, new technology, the increasing number of specialists involved in a patient's care, the aging patient population, the increasing prevalence and incidence of chronic diseases, and the ongoing management of *chronic* diseases using an *acute* care model. To bridge this gap in practice for the future, the IOM recommended that

all health care organizations, professional groups, and private and public purchasers should pursue six major aims; specifically, health care should be safe, effective, patient-centered, timely, efficient, and equitable. (IOM, 2001, p. 40)

Following the release of the IOM report, the BC Ministry of Health (MoH) initiated a process to strengthen the province's health care delivery system through the development of the *Primary Health Care Charter* (BC MoH, 2007). This collaborative approach to care provided a *guideline* to support the creation of a sustainable, accessible, and effective primary health care

system. It was the responsibility of each health authority in the province to *translate* the direction and priorities into a strategic plan for BC's health care system. The charter encouraged re-orienting "health services to align with the patient's journey through a patient-centred, integrated health system" (p. 1), and it introduced the principle of *patients as partners* in their care. Patients, families, and caregivers are partners in health care when they are supported and encouraged to participate in their own health care, participate in decision making about that care, participate at the level they choose, and participate in quality improvement and health care redesign in ongoing and sustainable ways (BC MoH, 2011, p.2).

In February 2014, the BC Ministry of Health set new priorities for the BC health system with the vision of supporting the health and well-being of citizens, delivering a system of responsive and effective health care services across BC, and ensuring value for money (BC MoH, 2014). Of the eight priorities that were set, providing patient-centered care was determined to be the highest one because it was "the foundational driver in the planning and implementation of all strategic actions in the health system strategy" (p. 27). For the first time, the MoH planned to assist with the translation of patient-centered care concepts into practice across the health system through the development of a framework that outlined both the overarching principles and the practices of patient-centered care (BC MoH, 2015). The principles of *dignity and respect; information sharing; participation; and collaboration* were foundational to the framework (p. 2). To further guide health care providers and organizations in patient-centered practices, the framework incorporated *organization-wide engagement, workplace culture renewal, balanced patient-provider relationships, and tool development* (p. 3). The MOH hoped that by developing a consistent definition and approach, this framework would

unify the vision of patient-centered-care throughout the province as the health system moved into the future.

Nursing Perspective

While patient-centered care appears to be the vision driving the recent history of medicine in BC and elsewhere, *person-centered care* underpins the practice of nursing. Medical practice has long been grounded in the identification of illness and its cause, and the introduction of measures that will, hopefully, cure an individual. Historically, nurses received no formal education and were the ones who carried out the tasks of treating the diseases. It was Florence Nightingale who differentiated nursing from medicine by its focus on the patient rather than the disease. She recognized the practice of nurses encompassed the patient's overall environment including warmth, ventilation, diet, pure air, pure water, cleanliness, light, the effects of noise, and the social environment.

The holistic nature of nursing is reflected in the following excerpt from Nightingale's notes:

In all these things, a convalescent is, so to speak, like a child; neither mind nor body has recovered its proper tone, and, for a certain time differing in different diseases, the nurse has to guide him by her own experience. She has this great advantage, that she has watched the whole progress of the case, from the point of danger up to that of recovery, and by keeping the whole chain in view she will be able to find the right course.

(Nightingale & Skretkowicz, 2010, p. 208)

Also, in distinguishing nursing from medicine, Nightingale focused on the concept of health and not illness:

There may be return to *life*; but return to health and usefulness depends upon the *after-nursing* in almost all cases. Careful nursing has done in a few weeks what uncareful medical observation has declared it impossible to do in less than two years. (Nightingale & Skretkowitz, 2010, p. 210; emphasis in original)

Nightingale's emphasis on the importance of observation, critical thinking, and reflection on practice, as well as the need for standard nursing education, became the cornerstone of modern nursing. Today, the discipline of nursing is expressed through a metaparadigm of four interacting components—person, environment, health, and nursing—with *caring* as the focus of practice (Fawcett, 1984). The *person* component focuses on the receiver of care; however, this extends to family and other carers who nourish the person socially and spiritually in a positive way. The *environment* component focuses on the internal and external surroundings that affect the person, including physical and social factors. The *health* component refers not only to the quality of well-being as defined by the person but also to the person's access to health care. Finally, the *nursing* component nurtures optimum *health* for *people* through mutual relationships in a caring *environment*.

Philosophical Underpinnings of Person-Centered Care

Since person-centered care is at the heart of nursing, it is instructive to review the philosophical underpinnings of the term and its link to nursing theory. In the next few sections I will explicate the philosophy of a person-centered approach to care, and explain how these ideas link to nursing.

Caring, supported by the philosophy of *humanism*, grounds a person-centered approach to nursing. Definitions of *humanism* have been shaped by varying religious influences throughout different time periods, such as the Renaissance and the Enlightenment, so the concept

has evolved over time. Today, *humanism* is defined as “a doctrine, attitude, or way of life centered on human interests or values,” or “a philosophy that usually rejects supernaturalism and stresses an individual's dignity and worth and capacity for self-realization through reason” (Merriam-Webster, 2015). Humanistic approaches assume that individuals are *capable* of giving meaning to circumstances that occur in their life and are able to make decisions based on those meanings (Hardin, 2001). In other words, the humanistic *self* positions individuals to be free to make choices in their lives.

How individuals find themselves situated or grounded in the world, and how they interact with others, is based on their ontological and epistemological assumptions. In the context of humanism, *ontology* is concerned with what human existence is, and *epistemology* focuses on what *knowledge* supports human existence, or what *methods* we use to understand human existence (Kim, 1999). To support the exploration of human existence and to narrow the knowledge gap related to what it means to exist, nursing theories today are significantly underpinned by the philosophy of existentialism and the method of phenomenology.

When we view the world through an existential lens, we focus on the meaning of human existence (ontology). Central concepts we consider are freedom and responsibility. Phenomenology views human existence through a different lens. The concepts of human *subjectivity* and *consciousness* focus the lens of phenomenology by considering a world in which existence is shaped by the immediate experiences of each person. Because things come to exist through consciousness, humans grow as meaning is attached to experience (Kim, 1999, p. 125).

When we combine the core existential concepts of *freedom* and *responsibility* with the phenomenological notions of *subjectivity* and *consciousness*, we are able to see the uniqueness of

each individual's lived experiences. These philosophies influence the relationships health care professionals experience and allow them to discern a person's *essence* and support their *choices*.

Link to Nursing Theory

Nurses are thirsting for a meaningful practice, one that is based on nursing values and knowledge, one that is relationship-centered, enabling the expression of the depth of our mission, and one that brings a much needed, missing dimension to current healthcare (Newman, Smith, Pharris, & Jones, 2008, E25).

The lens of humanism allows nurses to see people as *holistic* beings whose health is not the result of a sentinel event but, instead, the outcome of the biological, psychological, and social aspects of their life experience. This view fosters in us a desire to care for individual people—in my case, people living with HF—instead of leaving us to remain focused only on a medical disease or a curative approach.

Many nursing theories, such as those of Orem, Rodgers, and Parse, offer differing worldviews, but one theory I felt an instant connection to was Margaret Newman's Theory of Health as Expanding Consciousness, in which the practice of nursing is united by the nature of the nurse-patient relationship (Newman et al., 2008). The commitment to a caring relationship allows nurses to focus on the *meaning* of the current situation and appreciate the *pattern* of evolving forces that shapes *health*. It is the nurse's responsibility to be fully *present*, seeking to know what is *meaningful* to the person and allowing the pattern to unfold—Newman et al. wrote:

The fruitfulness of the encounter is a function of the nurse's commitment to an unconditional caring presence, openness, and perseverance in allowing action

possibilities to emerge. The relationship is embedded in a concept of health based on wholeness, evolving pattern, and transformation. (p. E17)

This nurse–patient relationship extends to family and other people who support individuals living with HF in the community. Through further knowledge of the individual, the appropriate support, management, and person- and family-specific navigation can be provided.

Whether it's Newman's theory or another theory, by itself or in combination, that resonates in practice, the result is that a richer and fuller management of HF can be achieved. This person-centered approach to care is nurtured by hearing and valuing the voice of the individual. APNs are well-positioned to establish partnerships with individuals, families, and caregivers by integrating their ontological and epistemological exploration; their knowledge of relationship-centered nursing theories, such as Newman's Theory of Health as Expanding Consciousness; and their ability to translate these theories into practice.

Patient-Centered Care in Practice

Although *patient-centered care* is a common term in health care, does it mean the same thing to all members of a health care team? How can someone determine if they are delivering a patient-centered approach in clinical practice? With these questions in mind, Kitson, Marshall, Bassett, and Zeitz (2013) conducted a narrative review and synthesis of health policy, medical, and nursing literature to identify the common, core elements of *patient-centered care*. Of the 60 papers included in their review, few contained common definitions of *patient-centered care*. The authors reduced the different phrases or descriptors associated with patient-centered care into categories and sub-themes until three main themes were identified: patient participation and involvement, the relationship between the patient and the health care professional (regardless of professional group), and the context in which care is delivered.

The first theme, *patient participation and involvement*, included the following sub-themes: seeing the patient as a respected and autonomous individual, developing a care plan based on the patient's individual needs, and providing care that addressed the patient's physical and emotional needs. The second theme, *the relationship between the patient and the health professional*, included these sub-themes: having a genuine relationship between the patient and the health professional; having the appropriate skills and knowledge to support the health professional's practice; open communication of this knowledge, personal expertise, and clinical expertise between the patient and the professional; and having a cohesive and co-operative team of professionals. The final theme, *the context where care is delivered*, consisted of one overarching sub-theme: *system issues*. The five categories encompassed by this sub-theme were the language used to describe patient-centered care, access to and perceived gaps in patient-centered care, supportive organizational systems, and therapeutic environment.

Statement of Problem

The work of Kitson et al. (2013), which I described in the previous section, established key elements of patient-centered care by integrating views of this approach according to health policy, medicine, and nursing, bringing attention to its complexity through the lens of the patient, the health professional, and the organization—in the *acute* care setting.

The work of Gerteis et al., which underpinned the work of the IOM on patient-centered care, was also done from an *acute* care perspective. Is it possible that the key elements of *acute* patient-centered care directly translate to a *chronic* disease management setting? In particular, how do APNs lead the implementation of a person-centered care approach to support the self-management of adult HF patients in an HFC?

Purpose of Project

The purpose of this project was to explore whether key themes of person-centered care could be identified to support the self-management of HF in the chronic disease management setting of our clinics. The specific objectives for this project were to (1) conduct a review of HF self-care literature with a person-centered approach, (2) critique articles to further limit inclusion criteria, (3) summarize articles in a table format, and (4) make practical recommendations that would allow an APN to lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC.

Part 2: Approach to Inquiry Research Methods

Research competencies of advanced practice nursing include identifying and conducting research that enhances nursing practice (Canadian Nurses Association, 2008). An integrative review method was chosen to achieve a comprehensive understanding of a person-centered approach in outpatients with heart failure. This type of review allowed for the inclusion of quantitative, qualitative, and mixed methodologies to gain a better understanding of a defined topic of interest to support evidence-based practice (EBP). I selected a methodology outlined by Whittemore and Knafl (2005) to strengthen the rigour of this research process. The five-stage process included problem identification, literature search, data evaluation, data analysis, and presentation.

Problem Identification

To clearly define my question in the *problem identification stage*, I used the Population, Intervention, Comparison, and Outcome (PICO) formula to help me develop a focused search strategy (Newhouse, Dearholt, Poe, Pugh, & White, 2007, p. 196). The selected population of

interest was adult outpatients in a Heart Function Clinic; the intervention was person-centered care; the comparison was the unstated usual care; and the measure of outcome was self-management of heart failure. The specific question I was seeking to answer was: *How do APNs lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC?*

Literature Search

The *literature search stage* used both electronic and ancestry searching. The electronic search was conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature On-line (MEDLINE), Google Scholar, and the Cochrane Database of Systematic Reviews. Keywords or phrases included in my search were *patient-centered care, client-centered care, patient-focused care, patient centered care approach, patient centered care method, heart failure, outpatient, self-management, self-care, decision making, empower*, motivation, and chronic disease management.*

I used the following inclusion criteria to narrow the selection of anticipated results: English language only, peer-reviewed, and time frame from 2001 to 2014 (as cited in DePalma, 2009, p. 228). I chose to include articles published in or after 2001 because this was the year the IOM report on patient-centered care was released. I felt this was the sentinel moment that grounded patient-centered care as an aim of health care delivery.

The initial literature searches generated a total of 446 abstracts; two additional articles were identified through other sources for a total of 448 abstracts. A total of 172 duplicates were removed from the list. The remaining 276 abstracts on the list were screened. Articles were excluded if they made reference to non-adults, palliative care, acute care, didactic education, home health monitoring, or cardiac rehabilitation, or were focused at an organizational level

instead of the clinician level. Articles were also excluded if they related to the development of psychometric tools related to measuring patient-centered care. Data sources from all health care professions were considered if they offered an approach that was within the scope of nursing practice.

I read the remaining 44 articles in their entirety to determine eligibility. These articles represented a patient-centered care approach to self-care for a variety of chronic diseases including diabetes, chronic obstructive pulmonary disease, arthritis, and heart failure. The distribution of these articles according to the years published can be seen in Figure 1.

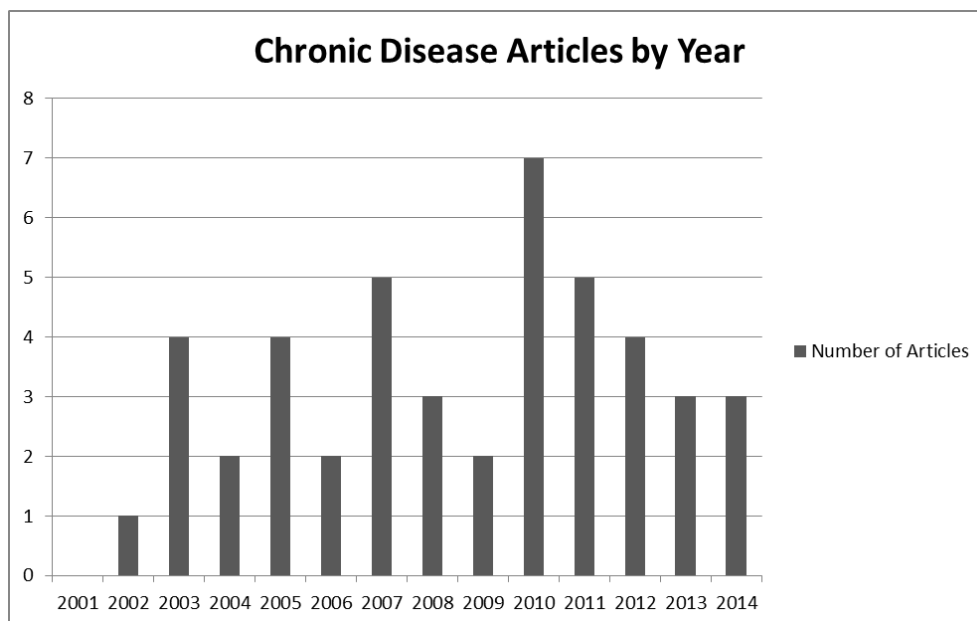


Figure 1. The distribution of study articles representing a patient-centered approach to self-care for a variety of chronic diseases according to year published.

While the articles provided a rich context of patient-centered care within populations having different chronic diseases, I was concerned about the generalizability to the heart failure population. With the exclusion of 27 articles that were non-specific to heart failure, I did a further critique of the remaining 17 articles.

I used Johns Hopkins' Evidence-Based Nursing Research and Non-Research Evidence Appraisal tools (Newhouse et al., 2007) to determine the strength and quality of the selected articles (see Appendices A and B for tools). Each article was critically and efficiently appraised according to the appropriate tool. During this stage of the data evaluation I was able to identify one article that was not related to patient-centered care, three that were not pertinent to my initial question of study, and two that were of poor quality. In total, 11 articles were included in the literature review. Figure 2 is a PRISMA flow diagram of this process.

Data Evaluation

Of the 11 articles evaluated for this review, the majority were published in the United States of America (6; 55%); equal numbers were from Canada and the United Kingdom (2 each; 18%); and the final article was published in Australia (1; 9%). Two of the studies (18%) used quantitative methods; one used a quasi-experimental design; and one a mixed methods design. The rest of the studies incorporated qualitative (64%) and non-research designs (18%) in the form of general literature reviews.

Data Analysis

To strengthen my *data analysis stage*, I began to reduce my data by determining an overall classification system as described by Whitemore and Knafl (2005, p. 550). As I had already narrowed my articles as to patient population and setting, I chose to analyze my articles chronologically. The remaining articles ranged in years of publication from 2006 to 2013.

This gap in the literature search made me reflect on why no articles were selected from the period 2001–2005. Of the six HF articles that were declined due to the previously defined criteria, only two of them appeared in the years preceding 2006 and were from 2004 and 2005 respectively. When I look at the 44 previous studies that included all chronic diseases, only 25

percent, or 11 of the 44 articles, were published before 2006. The lower frequency of articles in the years following the release of the 2001 report may represent the paradigm shift that occurred and perhaps reflects the time necessary to translate this knowledge into practice.

During my initial review of the study articles, I developed a worksheet and documented the following data for each article: research problem, design, sample size, intervention, results, and strengths and limitations. A summary of this information can be found in Table 1. I then analyzed my articles a second time through the lens of person-centered care, coding and extracting data from the primary sources into a spreadsheet. Identified themes and sub-themes were colour-coded in each article and entered for each primary source into a spreadsheet. This allowed me to make a comparison across each aspect of patient-centered care between each primary source. I recorded and reflected on this analysis using an electronic journal process.

Presentation

Finally, the *presentation* of my findings is in the format of a visual model (Figure 3) to illustrate the relationships between the key elements identified from the themes in the data (Figure 4). Accompanying the visual model are six key recommendations. The limitations and strengths of this integrative review were identified during this stage.

Findings

From the literature review I identified five themes critical to an APN leading the implementation of a person-centered care approach to support the self-management of adult heart failure patients in a Heart Function Clinic: (1) communication, including building relationships; (2) fostering understanding, including supporting patients seeking help; (3) encouraging problem-solving; (4) sharing decision-making; and (5) setting person-defined goals.

Theme 1: Communication

Communication was the foundational theme that grounded person-centered care. Effective communication allowed health care providers to build relationships by strengthening the professional–patient partnership (Riegel et al., 2006; Yu, Lee, Kwong, Thompson, & Woo, 2008). This was enhanced in an environment that provided support and acceptance to nurture mutual trust, and empathy, and to respect the patient’s dignity in a culturally sensitive manner (Riegel et al., 2006; Davidson et al., 2007; Schwarz, Cleenewerck, Phan, Bharadwaj, & Hobbs, 2011). Family practitioners were often selected by people to match their culture of origin in order to help the patient navigate a health care system that was foreign to them (Davidson et al., 2007).

The review of the literature identified three sub-categories that provided challenges to successful communication for patients related to emotions, family, and health care professionals. The experience of living with HF presented individuals with emotional obstacles to communication. Over time, people living with HF found that they adapted to feeling fatigued. They often reported to others they felt “fine” because it was too much to explain what the fatigue actually meant in their life (Jones, McDermott, Nowels, Matlock, & Bekelman, 2012). The extent of the fatigue could be so severe that it left people too exhausted to get together to socialize, which led to changes in both family and social roles.

Families supporting people living with HF also experienced challenges of communication. While they worked each day to support self-care at home, few were involved in clinical consults with professionals, and the person living with HF did not share information from the consults with their family (Clark et al., 2012). When families did attend consults and provided translation services, children in some cultures were hesitant to share all the details of

the condition because they were unsure how their parents would cope with the information about the HF diagnosis and prognosis. Children felt a responsibility to care for their ageing parents, and in one case perceived placing their parent in a nursing home as indicating they had failed their parent (Davidson et al., 2007).

Finally, people encountered numerous communication challenges with health care professionals on their road to HF self-management. Overall, communication was a challenge when the spoken language of the health care professional was different from that of the person with HF (Davidson et al., 2007). Regardless of language, people felt that their health professionals did not listen to them (Clark et al., 2012). When they did request information regarding their care, people perceived that their providers withheld information (Clark et al., 2012). Primary care physicians were seen as difficult to contact quickly, and both reception staff and health professionals were often perceived as being too busy to help HF patients (Gallacher, May, Montori, & Mair, 2011; Clark et al., 2012). People found it challenging to spend time trying to access specialty care for HF through their family physician (Gallacher et al., 2011). Once the HF plans of care were in place, people reported health care providers had poor communication with other health professionals (Clark et al., 2012). Those people who adhered to the recommended HF self-care guidelines felt their work of thought processes and related behaviours went unnoticed by their health care providers (Yu et al., 2008).

Theme 2: Fostering Understanding

The drive to *foster understanding* to improve person-centered care comes from identified gaps in HF knowledge and challenges in seeking information.

Knowledge Gaps

A review of the literature found that the term “heart failure” had no meaning for people with HF and their caregivers, and this could account for the inability to make a connection between HF and self-care behaviours (Davidson et al., 2007; Yu et al., 2008; Clark et al., 2012). It may also be responsible for the disconnect between HF and the development of symptoms. This lack of understanding sometimes led the family to urge health care professionals to consider left ventricular assist devices (LVADs) and heart transplants when these were neither medical possibilities nor aligned with the patient’s goals (Schwarz et al., 2011). Although this was a study of outpatients, inadequate discharge instructions were cited as a source of knowledge gaps for person-centered care (Riegel et al., 2006). Possibly this was the source of poor knowledge that was responsible for delays in seeking help (Clark et al., 2012).

Delays in seeking help seemed to fall on a continuum. Some people living with HF and their caregivers were uncertain what symptoms warranted help; some recognized their symptoms as worsening HF but didn’t want to bother health care professionals; some people hoped the unpleasant symptoms would go away, causing them to perceive the situation as less serious than it was; and some patients didn’t want to burden their caregivers with their concerns (Yu et al., 2008; Clark et al., 2012; Jones et al., 2012).

The impact of HF also had an effect on learning. The distressing symptoms and compromised physical functioning could lead to feelings of powerlessness and hopelessness. People found they needed to adapt to new roles in both their family and social environment (Yu et al., 2008). The most challenging aspect of the change in role that a diagnosis of HF brought included difficulty learning, thinking, monitoring, substituting, and remembering (Granger, Sandelowski, Tahshjain, Swedberg, & Ekman, 2009). People were unclear why certain tests had

been done or what the results meant. They were also not sure whether a treatment was working or not (Gallacher et al., 2011).

Information Seeking

The ambiguity of HF made it difficult for patients to make sense of their condition; therefore, patients wanted better explanations of HF and its symptoms from professionals (Yu et al., 2008; Clark et al., 2012). When people living with HF and their family did seek information independently on HF, they were challenged by the work of trying to understand what was available; the text of the information was often in small print, expressed with complex words, and only available in English (Davidson et al., 2007; Gallacher et al., 2011). People involved family and friends in the information-seeking process. At times, individuals would check to see if others thought their management plans were worthwhile before starting them, and then they would explore what these others thought about their progress (Gallacher et al., 2011).

Caregivers could also add to delays in seeking help by providing inaccurate information (Clark et al., 2012).

Emotional concerns limited people's ability to seek information. The work required to adjust to a new role meant individuals could need additional social support, and there was trouble accessing this resource (Gallacher et al., 2011). The symptoms of HF and its progressively deteriorating nature were especially distressing for those at a more advanced state of the illness due to issues of sudden death and living with uncertainty (Yu et al., 2008).

Theme 3: Encouraging Problem-Solving

Heart failure is a complex syndrome, and managing it takes more than just knowing what to do. People can only relate to their own experience of HF because they do not have the benefit of the lived experiences of other heart failure patients, as the clinic nurse does. Nurses have the

expertise and knowledge to solve problems for people; however, this does not encourage the person's problem-solving skills. While nurses provide information, build skills of patients and families, and activate supports as necessary, their role is to offer people options as they seek information to support their self-care needs. Developing these problem-solving skills helps individuals gain the confidence to make autonomous decisions about their care on their journey to personal acceptance of, and adjustment to, living with HF.

While some people lacked knowledge of HF self-care, others knew *what* to do but did not know *how* to manage the regimen of self-care in their daily life (Granger et al., 2009). Practical tips, such as using log books, records, and dosette boxes, helped people follow self-care regimens more accurately (Gallacher et al., 2011). Riegel et al. (2006) found role playing useful as it allowed people with HF to practice using newly acquired information in a safe environment and supported future problem-solving. This process of rehearsal can extend to sharing information with others; exploring possible options, such as how to manage a low sodium diet when going away for the weekend; or developing new plans of action related to self-care needs, such as increasing diuretics according to specific weight changes (Riegel et al., 2006; Riegel, Dickson, & Topaz, 2013). Role playing was an effective way to increase confidence and problem-solving skills.

Ongoing problem-solving support for people living with HF and their family helped with the adjustment process (Yu et al., 2008; Clark et al., 2012). While not all accepted their HF diagnosis, those who did seemed to make sense of the illness experience, accept the prognosis, and get on with living with the diagnosis (Yu et al., 2008).

Regardless of whether or not adjustment occurred, there were multiple roadblocks to developing problem-solving skills. People found that having to go out for multiple tests, clinic

appointments, and visits to the family doctor felt like work (Gallacher et al., 2011). Altering daily activities and their home situation required much effort and led to financial consequences (Gallacher et al., 2011). As symptoms, such as fatigue, progressed, it became too tiring to continue to manage their self-care needs themselves. When both physical and emotional reserves were exhausted, denial, avoidance, and feelings of powerlessness and hopelessness affected problem-solving abilities and were possible obstacles to managing HF (Yu et al., 2008). Although people with HF did not actively delegate this role to someone else, someone often took over the role of HF management for the person, which lessened their burden of problem-solving (Granger et al., 2009).

Theme 4: Sharing Decision-Making

Decision-making involves the process by which a person collects information from multiple sources and then makes a choice based on the transfer of knowledge. While certain factors influence the decision-making process (either encouraging or delaying it), the motivation to make decisions can be due to either internal or external locus of control. This study identified health, previous experiences, religion, and fears as internal motivators of decision-making.

When it came to health, people's decisions could be influenced by the dislike of their HF symptoms, including increased shortness of breath, increased fatigue, increased peripheral edema or abdominal bloating, and decreased exercise tolerance. People made self-care decisions based on past experiences, and those who assessed the situation as urgent were more likely to make a decision to act quickly when symptoms worsened (Riegel et al., 2013). Of note, however, was the finding that *similar past experiences* did not always lead to the *same decision* among different individuals or even in the same individual (Riegel et al., 2013). In addition, people relied on their intuition and perceived control to cope with HF symptoms as opposed to health

professionals (Clark et al., 2012). While it was unknown what effect personal spirituality, often a source of hope and strength (Yu et al., 2008), had on decision-making, as people aged or considered their mortality, religious and traditional beliefs frequently became more important to them (Davidson et al., 2007). The strongest motivator for self-care management decision-making, however, was the desire to stay out of hospital (Yu et al., 2008; Clark et al., 2012). This fear of hospitalization superseded the fear of HF symptoms (Clark et al., 2012).

People choose to take on this process of decision-making at different levels. Decisions by people with HF can be made in isolation, with the support of friends and family, or shared with health care providers. Not all patients wished to be autonomous in their decision-making process, or their desire for autonomy could fluctuate at different times. The uncertainty of HF, other illness characteristics that confounded symptom recognition, involvement of others, and past experiences resulted in a range of decision-making choices, from autonomous to dependent. Once people had shared the burden of living with HF with others, such as family, friends, and health care providers, these external loci of control assisted them. Family and friends were great contributors to the decision-making process, not surprisingly, based on the finding that people living with HF share the burden of their care with others (Granger et al., 2009). Some patients were willing to follow the advice of health professionals because they saw them as useful sources of support (Clark et al., 2012). Health professionals, however, found it difficult to work to improve decision-making with families who, in some cultures, chose not to disclose information about a HF diagnosis and prognosis (Davidson et al., 2007).

Some researchers found that as people adjusted to and accepted their diagnosis of HF, they made a conscious decision to live with the ever-present nature of HF (Yu et al., 2008). By building problem-solving skills with respect to self-care (see Theme 3), individuals became more

confident to make their own decisions, whether in isolation or with the support of their family and friends. This reflects the approach of the health care professional practicing from a humanistic approach, who tends to place the person with HF not only in the role of an active agent in decision-making but also in the role of the expert (Riegel et al., 2006; Schwarz et al., 2011).

Theme 5: Setting Person-Defined Goals

When health care professionals want people living with HF to consider planning for self-care, they are hoping the individual is mindful of fluid and sodium management, daily weights, taking their medicine as ordered, and balancing activity and rest. People, however, appeared to set both complementary and competing goals of care. Medications, diet, or exercise advice in relation to HF were considered and amended to fit in with planned schedules of activities on a day-to-day basis (Gallacher et al., 2011). For example, some people chose to take their diuretics after they returned from a morning outing or, alternatively, skipped the dose one day and doubled the dose the following day when they were not going out. The evaluations of these self-care decisions provided reinforcement for future decisions. Individuals contemplated what should happen based on their action and what to do if the expected outcome did not occur (Riegel et al., 2013). For example, a person's experience with fatigue gave them a sense of when they could anticipate this symptom, and they used this knowledge to set goals not only to protect their energy (Jones et al., 2012) but also to manage the expectations of family and friends, creating social and physical boundaries that helped the person with HF cope in their daily life.

Not all individuals possessed the knowhow to work toward a self-care goal, even when they were ready to do so. Motivational interviewing, a communication skill that can be used to develop a person's preferences and priorities, motivations for changing behaviour, confidence,

resources to engage in problem-solving and goal setting, and ability to evaluate any roadblocks to change, is potentially an important way to encourage self-care behaviours (Riegel et al., 2006; Evangelista & Shinnick, 2008; Paradis, Cossette, Frasure-Smith, Heppell, & Guertin, 2010). This technique is based on the stages of change (Prochaska & Di Clemente, 1982), which are used to determine how open a person is to making changes. In motivational interviewing, the responsibility for making choices to modify the behaviour resides with the individual. In the case of HF, a starting point with this technique is to invite the individual to choose the self-care behaviour they perceive as the easiest or most important to change (Paradis, et al., 2010).

The evaluation of outcomes of these self-care actions, either individually or supported by a health care professional, provided reflection points and reinforcement for future decisions (Riegel et al., 2013). People identified worsening symptoms, such as fatigue, shortness of breath, and depression (Yu et al., 2008; Granger et al., 2009), as barriers to goal-setting, which made self-care more difficult. This is in contrast to physicians' belief that HF symptoms were exacerbated by a lack of understanding of self-care (Granger et al., 2009).

Part 3: Discussion

The purpose of this integrated review was to examine recent literature to determine how APNs could lead the implementation of a person-centered approach to support the self-management of adult HF patients in a Heart Function Clinic, and to synthesize the findings into themes running through all the studies. Eleven studies were identified that investigated aspects of person-centered care and HF self-care behaviours, such as taking medications as prescribed, limiting fluid intake, limiting dietary sodium intake, weighing oneself every day, monitoring for worsening HF symptoms, and recognizing when it was time to seek assistance from a health care

professional. These studies were drawn from the 13-year review period following the release of the Institute of Medicine's (IOM) report *Crossing the Quality Chasm* (2001). This allowed me to examine the most recent literature regarding person-centered care and self-care behaviours in the adult HF outpatient setting.

This review identified five themes that APNs must integrate into their practice when leading the implementation of a person-centered care approach to support the self-management of adult heart failure patients in a Heart Function Clinic: (1) *communication*, including building relationships; (2) *fostering understanding*, including supporting patients as they seek help; (3) *encouraging problem-solving*; (4) *sharing decision-making*; and (5) *setting person-defined goals*. These themes are congruent with other definitions of person-centered care and self-management (Lorig & Holman, 2003). A Cochrane review of interventions that providers could use to promote a patient-centered approach in clinical consultations defined patient-centered care as:

A philosophy of care that encourages: a) shared control of the consultation, decisions about interventions or management of the health problems with the patient, and/or b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts (in contrast to a focus in the consultation of a body part or disease). (Dwamena et al., 2013, p. 2)

These themes were also seen in the recent definition by the BC Ministry of Health (2015):

Patient-centered care puts patients at the forefront of their health and care, ensures they retain control over their own choices, helps them make informed decisions and supports a partnership between individuals, families, and health care services providers. Patient-centered care incorporates the following key components: self-management; shared and informed decision-making; an enhanced experience of health care; improved information

and understanding; and, the advancement of prevention and health promotion activities. Patients, families and caregivers are partners in health care, supported and encouraged to participate in: their own care; decision-making about that care; choosing their level of participation in decision-making; quality improvement; and, health care redesign. (p. 1)

In the following sections, the five themes identified from the integrative review will be described to show how they underpin the expert coaching and guidance, consultation, clinical and professional leadership, and collaboration APNs use to support people dealing with the complexity of HF.

Communication

Communication, including building of relationships, is the foundation upon which all the other themes build. Empathy, genuineness, mutual respect, courtesy, positive regard, and joint participation are communication skills that help maintain the humanistic perspective which builds trusting relationships that will champion the values and beliefs of the individuals we care for (Chambers-Evans, 2002; Pelzang, 2010).

The skills of attentive listening, questioning, education, and information-giving are important in successful communication (Pelzang, 2010). These are some basic communication competencies necessary for clinicians to master in order to better understand the needs, wants, priorities, preferences, and expectations an individual or their family has for care based on beliefs, goals, and limited resources (Cumbie, Conley, & Burman, 2004). In an HFC, these communication skills are used both in face-to-face interactions in a clinical environment and over the phone during case management. Caring is impacted even when a person is in their home during phone follow-up (Eggenberger, Garrison, Hilton, & Giovengo, 2013), and it is not always *what is said* to the individual but *what is perceived to be done* for the individual, the

family, or their carer that strengthens the nurse-patient relationship. Detrimental to relationship building, however, was the lack of authentic caring connections in the present moment (Herbst, Friesen, & Speroni, 2013). The choice and implementation of nursing theory supports nurses as they build relationships with others in a caring way (O'Connell, 2008).

Even if the health care provider has skilful communication techniques, however, this literature review identified potential barriers between the provider and the person living with HF or their supporters. Sometimes communication could be challenging because of *emotional concerns*, including the effect of fatigue on socialization; because of *family*, including missed opportunities to share information, or as a result of cultural differences and language barriers; or because *health care professionals* were seen as the holders of the information or had poor communication with other professionals in the patient's health care team (Yu et al., 2008; Davidson et al., 2007; Gallacher et al., 2011; Clark et al., 2012).

Fostering Understanding

The second theme identified was *fostering understanding, including supporting help-seeking*. While some HFCs provide didactic, non-individualized education strategies (such as group education sessions), presenting material is not enough for knowledge transfer. Eldh, Ehnfors, and Ekman (2006) found that HF patients at a nurse-led clinic believed that their *participation* in their own care was equivalent to taking responsibility, obtaining the knowledge they lacked, and being treated like an individual. Nurses experienced *non-participation* of patients when individuals did not accept information or recommendations, and did not listen. This current literature review uncovered a variety of reasons why people may not be able to participate in their care, including symptom exacerbations; fatigue; cultural differences; adjustment challenges, including financial and social concerns; lack of understanding of what

“heart failure” means; and lack of clarity about what results indicate (Davidson et al., 2007; Yu et al., 2008; Granger et al., 2009; Gallacher et al., 2011; Clark et al., 2012; Jones et al., 2012).

People living with HF do not always want to receive information. Sometimes they don't even know what they want. For those individuals who are too overwhelmed to identify where their gaps in knowledge may lie, it is crucial to continue to build relationships with them and to work together to identify barriers to self-care. By getting to know the person better, it is possible to weave knowledge about different aspects of HF into every interaction (Fazio, 2013).

Including family and friends in educational discussions can facilitate and enhance self-care when others have taken on this work for people living with HF.

As nurses, we support those adjusting to a new diagnosis, an event, or a recent exacerbation of symptoms. People living with HF experience periods of uncertainty, anxiety, and fear as they struggle to learn what HF is and what it means to them. Until they arrive at the point where they feel confident they understand the disease and can manage the symptoms, follow the treatment, know when to call for help, and feel settled in their life, there are often emotional ups and downs that they experience. It is a time of adjustment; a time when people appreciate more support and an opportunity to talk to friends, family, and helping professionals as they work through the meaning of this disease in their life.

However, people, come to each situation in life with their own experiences. As nurses, who ascribe to phenomenology as a foundational philosophy, we are called to honour peoples' lived experiences, be mindful of the effect these experiences have on the current situation, and assess what each individual brings to their health experiences. Life concerns, including, but not limited to, finances, medications, depression, substance abuse, and challenging relationships, can interrupt a patient's ability *to take on the life role* of learning about HF or how to manage it.

Social support is often available in larger clinics in the form of social work, psychology, and psychiatry. When it is available, the option to refer to other health care professionals should be explored (Graven & Grant, 2014). Referral to these services represents an important part of adapting to the role of living with HF.

When people living with HF are open to receiving education and identify their area of concern, we must be clear, concise, and honest in our approach. Speros (2011, p. 329) suggested asking “what questions do you have?” as a good way to initiate this conversation. We must listen to each individual’s story and help them translate what “worsening symptoms of heart failure” means. The shared information should foster an individual’s health literacy by supporting their capacity “to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Somers & Mahadevan, 2010, p. 7). Three strategies to support people with lower health literacy are the use of plain language, the use of visuals, and the use of teach back (Black, 2008). The method of communication known as *teach back* is used to confirm understanding of shared information by asking people and their families to repeat instructions using their own words (Institute for Healthcare Improvement, n.d.). This *fosters understanding* by helping the clinician determine whether the message was clear or requires clarification. In BC, we use the HF Zones document (Figure 5) in HFCs as a management plan to help let individuals know when to seek help for worsening symptoms (Provincial Heart Failure Network, 2013b). At each clinic visit and during any phone management session with people living with HF or their supporters, nurses should encourage use of the language of the HF Zones by asking people to identify what zone they are in. If they identify the green zone, nurses can rehearse with them what they would do if they found they were in the Caution Zone to ensure they know they should seek help. This role-playing of a

potentially stress-provoking situation is a way to practise what people living with HF can say or do in specific situations. Modeling in this way can decrease anxiety and improve the knowledge transfer of a new skill (Lorig & Holman, 2003). Sometimes people are able to identify the correct zone but are unable to follow through with seeking help. This could be related to the hope that symptoms will go away in time, the desire not to bother anyone, or the lack of awareness that their HF symptoms are getting worse. Regardless, role-playing provides an opportunity to reinforce the option to call the HFC or their primary care provider, if needed. I share with individuals that our hope is to intervene in the Caution Zone before they move into the Danger Zone and need to go to the hospital.

Encouraging Problem-Solving

One of the core self-management skills described by Lorig and Holman (2003) was problem-solving. This aligns with the third theme identified in this project, *encouraging problem-solving*. Because self-management education is problem based, Lorig and Holman suggested that people should not be taught the solutions to their problems but, rather, basic problem-solving skills (p. 2). Working with the individual to define a problem, brainstorm possible solutions, implement one of the solutions, and then evaluate the response helps the individual build confidence in their ability to self-manage (Battersby et al., 2010). Enguidanos, Kogan, Keefe, Geron, and Katz (2011) found that people were more than twice as likely to solve their own identified problems as they were to solve problems identified by health care professionals.

As people transition from an acute health care model to a chronic care model, some become active participants in their care; however, some may continue in a passive role (Scruggs, 2009). Because the role of the expert does not belong to the health care professional, but to the

individual, nurses need to take an active role in supporting and coaching people on their journey of chronic disease management. The care of people living with HF relies on individuals or their supporters taking an active role in reaching out and seeking help when symptoms worsen. Only then do chronic disease management clinics, such as the HFC, or primary care practitioners know there has been a change in their condition between scheduled appointments.

The phone management component of care in an HFC constitutes a large part of the registered nurse's role. Case management using a person-centered philosophy supports an individual's problem-solving and, ultimately, shared decision-making (see the next section). It is faster to tell a patient what to do if their weight increases, but working with the patient to explore what *they* think the problem is, what *they* think the cause might be, what *they* think they should do, and then trying a solution and redirecting as necessary to correct misconceptions will help the person take on self-management more quickly and completely. Giving people living with HF these skills takes time, but it also gives them the confidence to adapt to a life with HF and manage by themselves.

Relationships are often built in a surprisingly short time at HFCs, and the lack of this connection represents an opportunity lost. Nurses working in HFCs rely on people living with HF or their support person to reach out when they need assistance; only then is there the opportunity to support problem-solving skills. By engaging in mutual reflection with people living with HF, and allowing time for independent reflection, nurses enhance the potential to problem-solve through the process of co-creating person-specific knowledge (Zoffmann, Harder, & Kirkevold, 2008).

Sharing Decision-Making

The fourth theme, *sharing decision-making*, relates to an individual having a voice in their health care planning (Opie, 1998). In the context of this project, the concept of sharing decision-making can be transferred to making plans about self-care in an HFC. Placing the person living with HF in an active role, where they are viewed as the expert, supports the shared decision-making process. Barriers that can make it challenging for individuals to transition to an active decision-making role are well-documented and include a person's depression, cognition, education, physical condition, stressors (including financial concerns), social support, communication style, and relationship with the nurse (Schnell, Naimark, & McClement, 2006; Rees, May, & Rae, 2010). A further stumbling block can arise when professionals choose to remain within a disease-related focus when people would rather address life-related issues (Zoffmann, Harder, & Kirkevold, 2008). Also, not all people living with HF want to take on this active role. Some choose to be passive decision-makers, releasing their control of this process to the health workers who they expect to be "the experts" (Matlock, Nowels, & Bekelman, 2010; Lawn, McMillan, & Pulvirenti, 2011).

Not only is an individual's decision-making shared with health care professionals in an HFC, it can also be shared to different extents with family, friends, and other supporters. Those individuals who accepted their HF diagnosis were able to make a decision to live with the ever-present nature of HF (Yu et al., 2008). An awareness of an individual's perspective concerning these HF challenges may help nurses understand the self-care decisions that are made and may assist with the transition from passive to active decision-making (Zoffmann, Harder, & Kirkevold, 2008; Matlock, Nowels, & Bekelman, 2010). Self-care decision-making in people who had adapted to living with HF was informed by previous experience, religious beliefs,

intuition, and perceived control (Clark et al., 2012). And the decision-making process of some people living with HF was strongly motivated by their desire to stay out of hospital (Yu et al., 2008; Clark et al., 2012).

Shared decision-making requires skilled communication between an individual and a health professional within a therapeutic, caring relationship to ensure an individual's own decisions are valued (Opie, 1998; Slater, 2006). Although decision-making capacity can be improved through the awareness of communication styles, psychosocial support, and practical support, shared decision-making does take time (Opie, 1998; Rees, May, & Rae, 2010). Zoffmann and Kirkevold (2012) discovered that while professionals discussed their patients' challenges with each other, they did not share their thoughts with the patient. Being open and honest about our thoughts and concerns in the clinic opens the door for mutual reflection and further supports the shared decision-making process.

Setting Person-Defined Goals

The final step in a shared decision-making process is the individual's actual choice and implementation of a self-determined plan for the future. This process of *setting person-defined goals* constitutes the fifth identified theme. People who had adjusted to living with HF were able to take on the role of an active participant in their self-care. Although sometimes taking a different path from what health care professionals might wish to see, people living with HF considered and amended advice with respect to how medications, diet, exercise, or balancing rest and activity could fit in with planned schedules each day (Gallacher et al., 2011; Jones et al., 2012). An important step in these self-care decisions was to evaluate the outcomes. Individuals contemplated what should happen based on their chosen action and what to do if the expected outcome did not occur (Riegel et al., 2013). *Setting person-defined goals*, as identified in this

project, is supported in other chronic disease management literature (Bédard, n.d.; Glasgow, Davis, Funnell, & Beck, 2003; Wagner et al., 2005). Setting specific behaviour change goals according to an individual's priorities should be based on their interest and confidence level. Individuals are then assisted in developing personal action plans to meet their goals (Glasgow, Davis, Funnell, & Beck, 2003, p. 566). Two important components of follow-up with respect to an individual's goal attainment are the arrangement of future follow-up with the person, and the sharing of goals with all members of the team so the goals can be reinforced.

As previously discussed, not all people have made the transition to this active decision-making and goal-setting role for a number of reasons. One method to support a person living with HF to set goals as a way of increasing self-care behaviours was with the technique of motivational interviewing, based on the stages of change (Riegel et al., 2006; Evangelista & Shinnick, 2008; Paradis, et al., 2010). This technique has been used in many settings (Droppa & Lee, 2014). Specifically, motivational interviewing showed promising results in improving self-efficacy in older people with HF (Falk, Ekman, Anderson, Fu, & Granger, 2013). Again, evaluation of outcomes of these self-care actions, by the individual alone or with the support of a health care professional, provided reflection points and reinforcement for future decisions (Riegel et al., 2013).

Interaction of Themes

While the overarching theme of *communication, including building of relationships*, underpinned the other four themes, the themes were not mutually exclusive. Nor do people with HF or health care providers move through these themes in a linear fashion. Instead, variable interconnections exist between all the themes; so, for example, *fostering understanding* can lead

to *encouraging problem-solving*; or *setting person-defined goals* can lead to *fostering understanding*; or *sharing decision-making* can lead to *encouraging problem-solving* (Figure 4).

The person-centered approach described here recognizes the person as an individual, not a disease. It diminishes what may be seen as a hierarchical professional relationship that is created when a health care provider views the individual as a patient or disease (Slater, 2006). The nurse-patient relationship is one of individuality and sharing. The expertise and knowledge of the nurse support the personal decisions made by an individual with respect to that individual's care. This shared insight into decision-making improves the opportunities for a nurse to support individuals in developing self-management of a chronic illness, such as HF (Zoffmann, Harder, & Kirkevold, 2008).

Implications for Practice

An important aspect of HF chronic disease management is self-management, which includes recording daily weights, taking medications, limiting fluid and sodium intake, and seeking help when symptoms worsen. In a specialty area such as an HFC, registered nurses who traditionally practice from a caring and humanistic focus can become drawn into the disease-focused model of medicine so this project focused on how APNs lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC, which has traditionally included the medical management of HF. By choosing to search the outpatient HF literature to identify specific themes that could support self-management with a person-centered approach instead of only person-centered care, this project has made a practical application more tangible, as opposed to theoretical. The result of implementing a person-centered approach is to shift the power from the traditional role of the health care provider to the individual.

APNs lead in the HFC by applying their expertise in HF, supported in BC by the HF-CAPE tool (Provincial Heart Failure Network, 2013a), to tailor the learning needs of each person living with HF, their family, or their carer. Through *communication, including building relationships*, APNs are well-positioned to implement a role of expert coaching and guidance by *fostering understanding*, including supporting individuals as they seek help; *encouraging problem-solving; sharing decision-making; and setting person-defined goals*. Figure 3 illustrates an evidence-informed model of the person-centered care approach to support the self-management of adult HF patients in an HFC. This model was created as a practical tool for knowledge translation. Asking “What can I help you with today?” shifts the locus of control to the individual. Although both physical and emotional factors may affect the answer to this question, chronic disease management literature and my own experience has led me to the creation of four categories or stages of response: overwhelmed, information gathering, action, and maintenance (Lorig & Holman, 2003; Hibbard, Stockard, Mahoney, & Tusler, 2004; Mosen et al., 2007; Hibbard, Greene, & Tusler, 2009). APNs are well-positioned to support these stages through expert coaching and guidance, consultation, clinical and professional leadership, and collaboration.

Communication, including building relationships, is vital throughout these stages.

Coaching and Guidance

When someone tells you that “everything is fine” and they are “doing well,” the person with HF may be stable and managing well, or they may not be managing at all. To correlate the stage of the response with what the person is saying, APNs integrate their ontological and epistemological exploration, their knowledge of relationship-centered nursing theories, and their HF expertise. If your expertise indicates some symptoms of HF are incongruent with what the person is saying, the previous relationship that you have built with individuals, families, and

caregivers, is very important. Share your concerns in a non-confrontational manner and identify how your assessment, including any blood work results, indicates worsening HF. Your concern has the potential to plant a seed for the individual that can result in mutual reflection with a member of the multidisciplinary HFC team, or independent reflection at a later time. APN's expert coaching and guidance of people with HF is complemented by resources such as the HF Zones and the *teach back* method. When people are truly stable, review the HF Zones and share any new resources.

Consultation

Consultation is demonstrated by engaging clerical staff, registered nurses, and the specialties of other disciplines, such as exercise specialists, dietitians, social workers, psychologists, and physicians to enrich the person-centered care approach. Because our HFC is a multidisciplinary clinic, one of the nursing roles we have initiated there is weekly consultation with the exercise specialists about people who attend both the high-risk exercise program and the HFC. *Building relationships* with other professions is of benefit to APNs, and the resulting consultations allow them to provide further expert coaching and guidance where necessary.

Building relationships also provides an opportunity to involve other professionals in a person-centered approach. While not all people in the HFC utilize all the services offered in a clinic, when someone does take advantage of social work or psychiatry services offered, the nurse should look for notes or consultations following these visits. Often, regular consultation rounds with these specialties are a challenge, as they work only part-time with clinics.

Initiate the practice of documenting an individual's values and preferences. Information shared with one member of the team by the patient, can be shared with other team members through this documentation process.

Finally, consultation with the primary practice team member is especially important for an APN. Although this project has identified the need to see the person and not the disease, people are ultimately referred to an HFC in the context of HF. It is possible the family practitioner has the experience, even though disease-related, of knowing the person in other contexts, which can give APNs further insight into how people cope in different situations.

Clinical and Professional Leadership

APNs guide a person-centered care approach to support HF self-management through both clinical and professional leadership. They advocate for the person. As people answer the question “What can I help you with today?” APNs use their expertise in clinical content and chronic disease management to co-ordinate services for people living with HF. Stronger relationships are built, as APNs provide a clear commitment to the concerns of people living with HF and help them navigate the health care system. In our HFC, we have experienced an unexpected outcome of intra-professional leadership by providing case management within a shared space. This has exposed my colleagues to the modelling of a person-centered approach that they would not otherwise have been privy to in a clinic setting. It sets the groundwork, at a clinical level, for the development of an approach to standardize person-centered care and to collectively create a plan of change to fully implement in practice a model such as the one in Figure 3. By working with the multidisciplinary team, the interactions with the person living with HF and their family are enriched as the team resources are built.

Collaboration

APNs collaborate to develop partnerships and involve other health care team members to impact care for the benefit of the individual and their family. Heart failure is a complex syndrome, and people living with HF can be high users of health care services. Establishing who are the other members of an individual’s health care team is important in order to facilitate the

communication of test results, appointments, and plans of care, and to collaborate and consult as necessary. It is not unusual to develop partnerships with other cardiologists; specialists; other clinics, including dialysis, pre-heart transplant, pacemaker, ICD, and other HFCs; home and community care; and palliative care.

Also, as this project identified, family practitioners were often selected by people to match their culture of origin so that they could assist the person as they navigated a health care system that was foreign to them. APNs should consult and collaborate with family practitioners to advance their understanding of potential cultural challenges to self-management.

Recommendations

APNs can lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC by developing an evidence-informed practice model (Figure 3) and integrating the following six recommendations:

Recommendation 1: Building the relationship through trust, respect, and empathy in a culturally sensitive manner strengthens the partnership between the nurse and the individual.

Recommendation 2: As health care practitioners, we have gained collective knowledge and experience from many people living with HF. People only have *their own* HF experience to draw on and are unable to place the meaning of their symptoms in the context of the HF trajectory. Listen to the individual's experience of HF and bring your nursing experience to help them navigate the challenges that accompany processing new HF information.

Recommendation 3: Lack of knowledge delays seeking help. Clear, concise communication, using health information that is understandable and culturally accessible, should be shared with patients and their family, including at the time of discharge from hospital. It is recommended the province of BC work with community groups and family physicians who possess conversational and written second languages to translate the HF Zones into alternate languages for use throughout the province.

Recommendation 4: Providing education alone will not have a positive impact on self-care behaviours. People living with HF need practical support to translate the knowledge of what to do to manage their HF in their daily life. Offer social supports to help patients adjust at any point along the HF journey. Rehearse with a patient how they would be able to adopt the new

skill into their life. Work together to develop plans of action based on the patient's experience or changes in symptoms, and remember to evaluate the outcomes.

Recommendation 5: People living with HF are the experts on themselves. Their decision-making process is dependent on their wish for involvement. The characteristics of uncertainty, urgency, illness, and involvement of family, friends, cultural and religious influences, and health care professionals have a strong influence on sharing decision-making. Clinicians need to share the power of decision-making with HF patients in a supportive environment to promote future problem-solving.

Recommendation 6: Some people living with HF are able to manage self-care behaviours of HF and some require the support of their family and friends. Worsening symptoms, such as shortness of breath, fatigue, and depression, and not just a lack of knowledge, make it more challenging to carry out self-care. Motivational interviewing, based on readiness to change, may help support those who require guidance with developing a HF plan. Evaluating the outcome will provide reinforcement or new plans for future decisions.

Limitations and Strengths

This study had several limitations. First, there was only one person involved in the analysis of this research. A much fuller and richer outcome might have been possible if there were more researchers to consult and collaborate with on such a project, as each additional person would have brought a different outlook on the subject based on their expertise and lived experiences. Although I have more experience and am, therefore, more comfortable *collaborating* on projects, this project has brought me great professional growth in independent project work, including writing and person-centered care. As I slowly progressed on my project, I wondered if looking at a person-centered approach in an HFC would have allowed me to bring this project to a quicker conclusion than my choice of a person-centered approach to self-care. However, over the course of this project I have come to believe that the initiation of self-care teaching in an HFC has the potential to detach nursing practice from a person-centered approach and lead to an alignment with a disease-focused medical model. If I had not included this in my

project, I may have missed this crucial learning opportunity. While it provided me with a great, long-term challenge, I appreciate making this valuable connection.

Second, a bias was introduced as I scanned the articles to determine which ones would meet the inclusion criteria. I realized I had a preconceived notion of what it meant to provide a patient-centered approach. It has been through this project that I am now able to articulate what patient- and person-centered care means both ontologically and epistemologically. Upon concluding my research, my interpretation of person-centered care is now fuller and richer than it was before I began this study. This transfer of knowledge strengthens my ability, as an APN, to lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC.

Third, potentially because of the bias introduced by my preconceived notions of patient-centered care, the final study sample was small (n=11), and this has limited the depth and scope of these results. Although 44 articles pertaining to self-care and chronic disease were identified within the inclusion dates, all those not specific to HF were eventually excluded to improve the generalizability to the HF population. I was left, however, with an obvious gap in literature to review. The first article included in the final project was published in 2006. Possible reasons for this were explained earlier, in the methodology section.

The principal strength of this review was the methodology selected to strengthen the rigor of the research process. By following a methodology outlined by Whittemore and Knafl (2005), my research was well-supported as I moved through the stages of problem identification, literature search, data evaluation, data analysis, and presentation in the form of a practical tool to support knowledge translation. Within this methodology, research articles pertaining to a single population of interest were all critiqued using a systematic evaluation of the quality. The

generalizability of the results was strengthened by narrowing the sample articles to those pertaining to the self-care of HF, instead of all chronic diseases. Regardless of the small sample size, data saturation did occur, and the identified themes were supported by other chronic disease literature. My process of coding and extracting data from my primary sources into a spreadsheet also strengthened this review.

Finally, while not a strength of this research, the process of being the sole researcher on this project has strengthened my research competencies as an APN and will support my future research and my mentoring of others. Being the only one to become so intimately involved with the data of the project granted me the autonomy to identify the themes that were presenting themselves to me based on this integrated review and my experience with my population of interest. Through great challenge comes great learning. I have been professionally fulfilled by this experience.

Conclusion

Many health care professionals practise in a hospital environment, even in outpatient clinics such as an HFC. Hence, the use of the word *patient* continues in our lexicon, and the expression *patient-centered care* is becoming more established. *Person-centered care* is a more humanistic term with underpinnings of caring associated, historically, with nursing practice. Regardless of the terminology, medicine seems to be adopting the attributes of nursing practice that produce a holistic approach to delivering care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship in which individuals receiving care are empowered to be involved in health decisions at whatever level they desire (Morgan & Yoder, 2012, p. 8). In medicine, chronic care management has always been disease-oriented, which means the discourse of healing and curing plays an important role (Wilce, 2009;

Starfield, 2010). Because there is no cure for HF, an APN in collaboration with the multidisciplinary team in an HFC is an ideal person to lead a holistic, humanistic approach of person-centered care.

An important aspect of HF chronic disease management is self-management, which includes taking daily weight measurements, taking medications, limiting fluid and sodium intake, and seeking help when symptoms worsen. The focus of this project was to determine how APNs could lead the implementation of a person-centered approach to support the self-management of adult HF patients in an HFC. Following an integrative review of HF self-care literature with a person-centered care approach, the data were reduced until five themes were identified: (1) *communication*, (2) *fostering understanding*, (3) *encouraging problem-solving*, (4) *sharing decision-making*, and (5) *setting person-defined goals*. While the overarching theme of *communication, including building of relationships* underpinned the other four themes, the remaining themes were not mutually exclusive; they were interconnected but not in a linear fashion. Although this study was of small size (n=11) and is not generalizable to all aspects of person-centered care, the results were well-supported by current chronic disease management literature on self-care.

As with any specialty clinic, HFCs are not meant to provide care to all people living with HF. The majority are managed by primary care. The purpose of an HFC is not to care for people living with HF from the time of their diagnosis until the end of their life. Unfortunately, there are a finite number of people who can be cared for in a clinic due to the limited resources of HF specialists, registered nurses, and supporting staff. Advanced practice nurses are well-positioned to support the complexity of HF through expert coaching and guidance, consultation, clinical and professional leadership, and collaboration both intra- and inter-professionally. The

role of an HFC is to provide knowledge and skills as needed; to share the power of decision-making in a supportive environment, in order to promote future problem-solving; and to assist people to define their goals of care, so they can continue to be managed in the community by their family practitioner.

This study provided a preliminary description of a person-centered care approach to support the self-management of adult HF patients in an HFC. Although the environment of empathy, respect, mutual trust, and cultural sensitivity was found to be consistent in both acute and chronic care, the long-term relationships that are built in the HFC support *fostering understanding*, including supporting people seeking help; *encouraging problem-solving*; *sharing decision-making*; and *setting person-defined goals*. Future research should be directed towards the implementation of this integrative review of person-centered care into practice in an HFC. A deeper understanding of McCormack and McCance's (2006) nursing model of person-centeredness could support the implementation of this process of change.

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Table 1: Summary of Articles (n = 11)

Author (year)	Setting	Sample (Male/female)	Methodology	Data collection and analysis	Key findings	Strengths (+) and weaknesses (-)
Riegel et al., (2006)	Major tertiary center in USA	n = 15 (6m/9f) age range 46-73 NYHA class: II = 10/15 III = 3/15 IV = 2/15	Mixed methods - pretest posttest design	Survey Tools Interviews - Participants received, on average, 3.0 +/- 1.5 home visits over a 3-month period from APN trained in motivational interviewing	71.4% showed an increase in one of the SCHFI subscales or the SCHFI total by 8 or more points after receiving motivational intervention. Intervention revealed themes of: <i>1. Communication style:</i> reflective listening, expressing empathy <i>2. Making it fit:</i> Acknowledging cultural beliefs; overcoming barriers & constraints; negotiating an action plan <i>3. Building the transition from hospital to home:</i> providing information; building skills; activating support resources	+ Concordance of mixed methods + Intervention delivered by same APN who received extensive training - Missing quantitative data from 6/15 people - Small sample size
Davidson et al., (2007)	Rural Australia of Chinese, Serbian, Croatian, Macedonian, Arabic, Greek, Russian cultural	Family groups (n = 13) Key informants (n = 16) HF CNS (n = 8) Community focus groups (n = 6)	Ethnographic -exploratory, observational	Interviews of unknown format, observations, field notes - themes derived by triangulation - data analysis using content analysis	Culture provides context to interpretation attitudes, values, beliefs and behaviours, in illness and health. Family is important in making decisions about treatment choices and care plans. The GP plays a critical role in assisting people with the health care system. Cancer feared more than HF. Religious/holiday beliefs are more important as people aged and considered their mortality	+ Common themes identified across 5 data sources - Poor description of population - Unclear methods of recruitment or how key informants selected - Not all patients in community focus groups had heart disease
Evangelista & Shinnick (2008)	Unknown	n = 22 articles male/female unknown	Literature review of randomized controlled trials	Electronic search of databases - RN-delivered HF management programs that measured effects on self-care behaviour adherence - "Carefully reviewed"	Complex needs of HF patients require effective educational, behavioural, and psychological interventions that integrate strategies that motivate, empower, and encourage patients to make informed decisions about self-care.	+ Included studies were HF disease management programs delivered by a nurse + Sample size adequate + Discussion well described - Data analysis not defined. - No table to compare studies. - No mention of fluid management in HF guidelines of self-care - No identification of own limitations.
Yu et al. (2008)	Varied: HFC; general medicine clinic, general practice, outpatient clinic, local hospital, palliative advanced home care	n = 14 articles Age range 47-90; distribution of male and female unknown	Systematic review of qualitative studies	Electronic search; manual search - thematic data analysis guided by transactional model of stress	HF characterized by distressing symptoms, compromised physical functioning, feelings of powerlessness and hopelessness, and social and role dysfunction. Gender differences occur in way HF conceived. Adjustment requires one to make sense of illness experience, accept prognosis, and get on with living with HF.	+ Methodology process clear + Data analysis clearly explained - Some patients not that old (range 47-90) for study on "older people" with HF

Author (year)	Setting	Sample (Male/female)	Methodology	Data collection and analysis	Key findings	Strengths (+) and weaknesses (-)
Granger et al. (2009)	From Duke University Hospital, an academic medical centre.	6 dyads (pts with HF & their cardiologists) 6 pts (5m/1f) Mean age 58 years NYHA class III/IV	Descriptive of dyad experiences	Semi-structured interviews analyzed using content analysis guided by the Trajectory Theory	Patients knew key components of HF regimen; however, unable to translate knowledge into action. Both pts & MD delegate much regimen-related work. Patients' ability to accomplish the work alone limited, particularly during symptom fluctuations & exacerbations.	+ Theoretical framework informs interview guide and analysis + Unique focus on patient/physician dyad - Small dyad sample
Paradis, et al. (2010)	Heart Function Clinic patients in large tertiary centre	n = 30 (22m/8f) age range 50-91 yrs NYHA class: I = 1/30 II = 17/30 III = 12/30	Experimental design – pilot study	Chart review; survey; pre-post tool measurement of SCHFI (subscale A, B, C), Therapeutic Self-care Scale, Confidence & Conviction Scale (subscale 1,2)	HF pts were asked to select one self-care behaviour they would like to change among 5 common HF self-care behaviours. An intervention that combines motivational interviewing and readiness to change, received once in person, and twice by phone, resulted in increasing confidence to perform self-care behaviours at one month and has the potential to encourage self-care behaviours in HF patients.	+ Algorithm of intervention transparent - Project RN trained with intervention expert - Unsure if reliability of tools affected by translation into French - Unexplained lower coefficient α for study Confidence & Conviction Scale than in general - Pilot study; however, 5/30 lost to follow-up
Schwarz et al. (2011)	Chronic HF patients	Non-research article	Philosophical argument	Expert opinion	A more humanistic approach to HF is based on the patient being seen as active in the situation. It is based on the pt/family recognizing symptoms and adjusting care; an empathetic and co-operative approach; respecting patient's autonomy; and the realization that treatment strategies and outcomes may be affected by health, disease, suffering, and existential values.	+ Identifies limits to active self-care in HF patients + Introduces link between holism and patient-centered care - Medical focus - Non-research study
Gallacher et al. (2011).	Patients with chronic HF in primary care in UK	n = 47 (29m/18f) Aged 45-88 (mean 73)	Theory-led qualitative analysis	Secondary analysis of interview data using framework analysis informed by Normalization Process Theory	HF treatment burden includes the work of learning about treatments and the consequences; engaging with others to organize care; adhering to treatments and lifestyle changes; and monitoring treatments.	+ Data analysis + Large sample size + Interview guide available - Emotional work omitted from theoretical framework - No recruitment details of sample in primary analysis; sites unknown - Burdens unverified or ranked by patients (2 ⁰ ry analysis)
Clark et al. (2012)	Varies but includes: Outpatients; acute care settings; record reviews in USA, Sweden, UK, Australia, Canada, Iran, the Netherlands, & NZ	58 qualitative studies 990 patients; (527m/274f/189 unknown) 229 caregivers, 79 health professionals	Systematic review using meta-synthesis	Electronic search; reference lists; consulted with colleagues; papers screened for quality with CASP tool	Help-seeking a multi-stage process. Symptoms confusing and ambiguous with little available support from professionals to interpret. Help-seeking facilitated by effective communication and sense of elevated personal risk.	+ Clear data collection and analysis + Detailed presentation of results + Diverse HF sources in sample - Included 12/58 low quality and 11/58 low to moderate quality in sample without justification

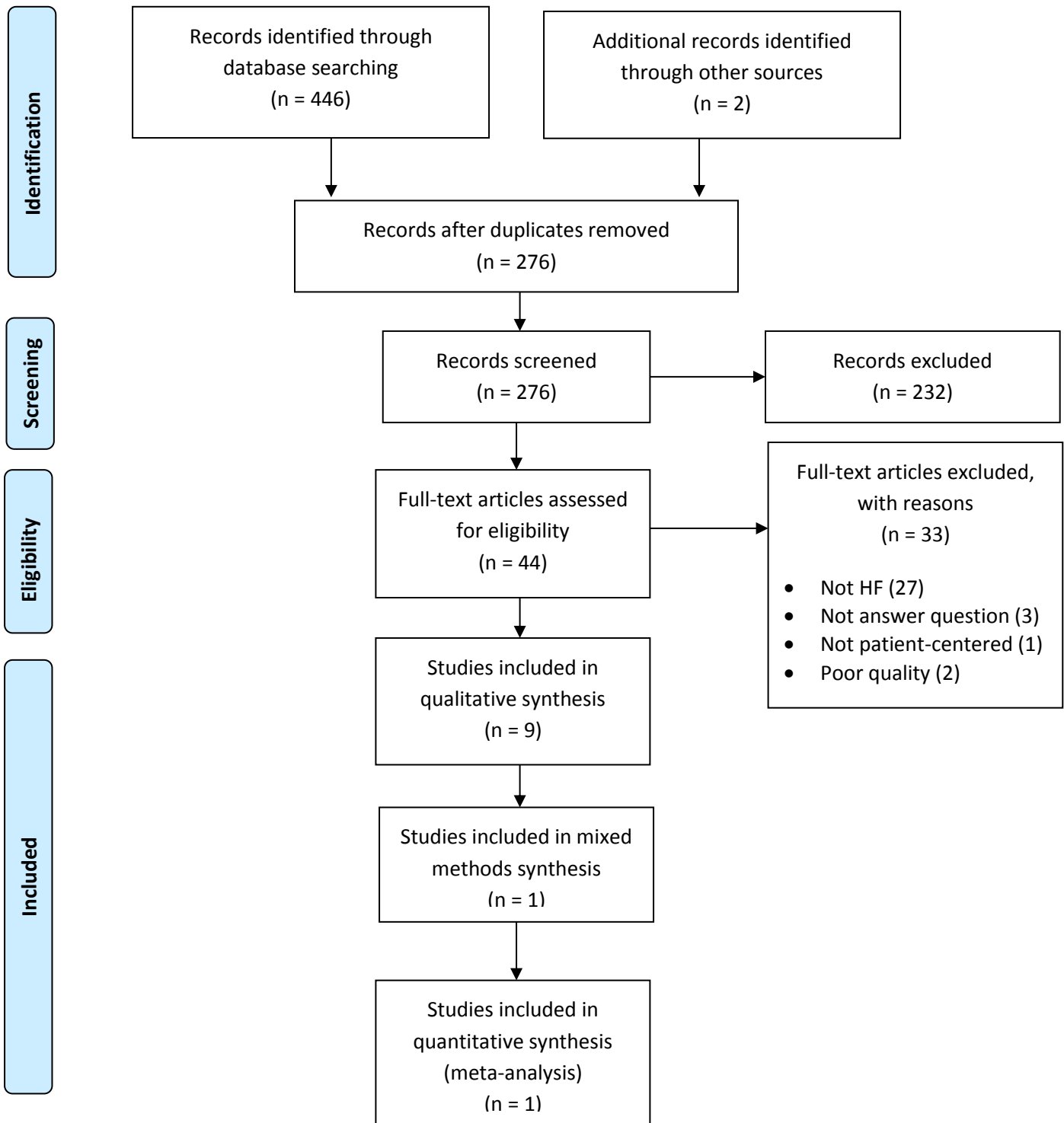


Figure 2. PRISMA flow diagram showing study identification process. From: Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analysis: The PRISMA Statement. *PLoS Med*, 6(6): e1000097. doi:10.1371/journal.pmed1000097

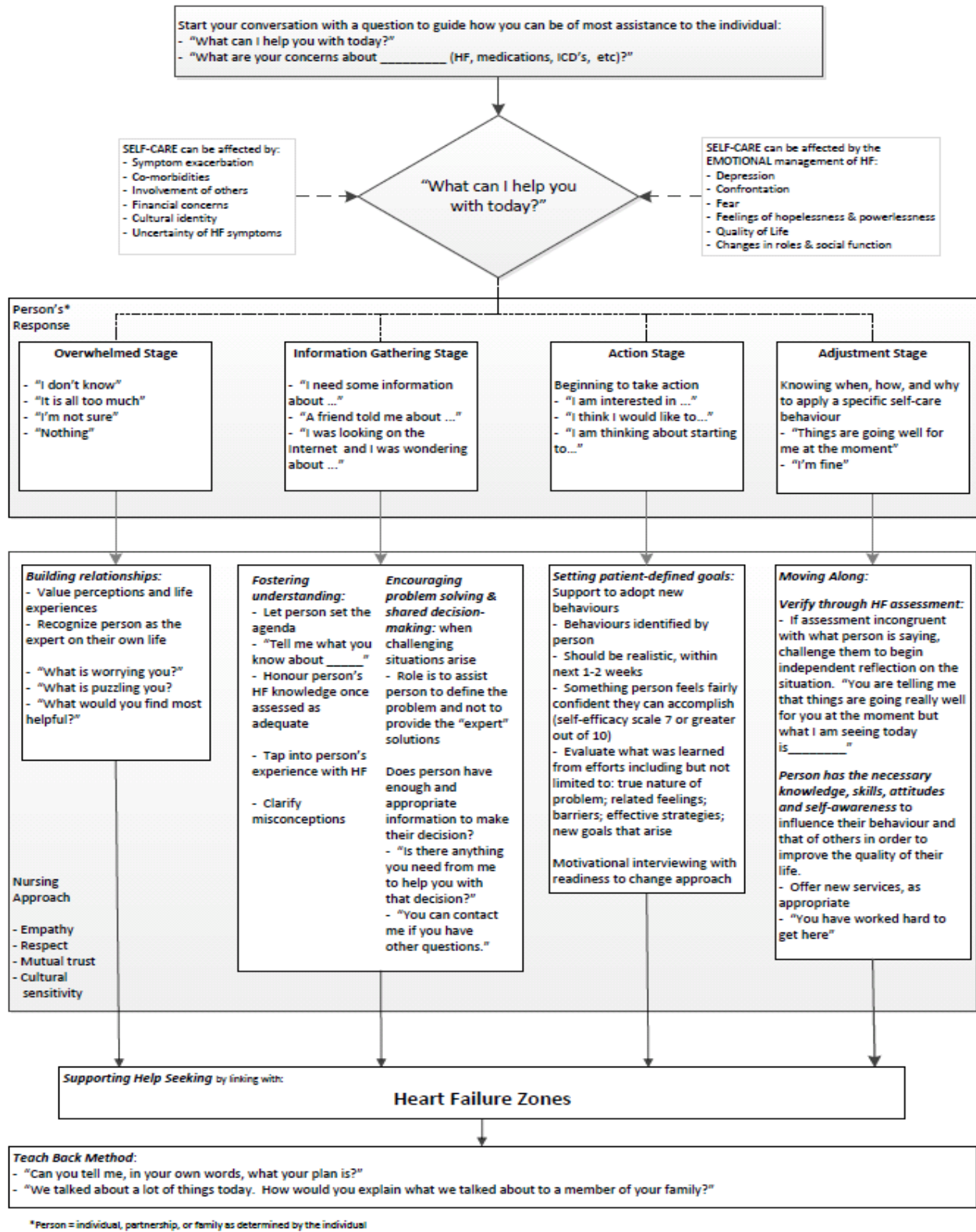


Figure 3. Evidence-informed model of person-centered care approach to support the self-care of adult HF patients in a Heart Function Clinic

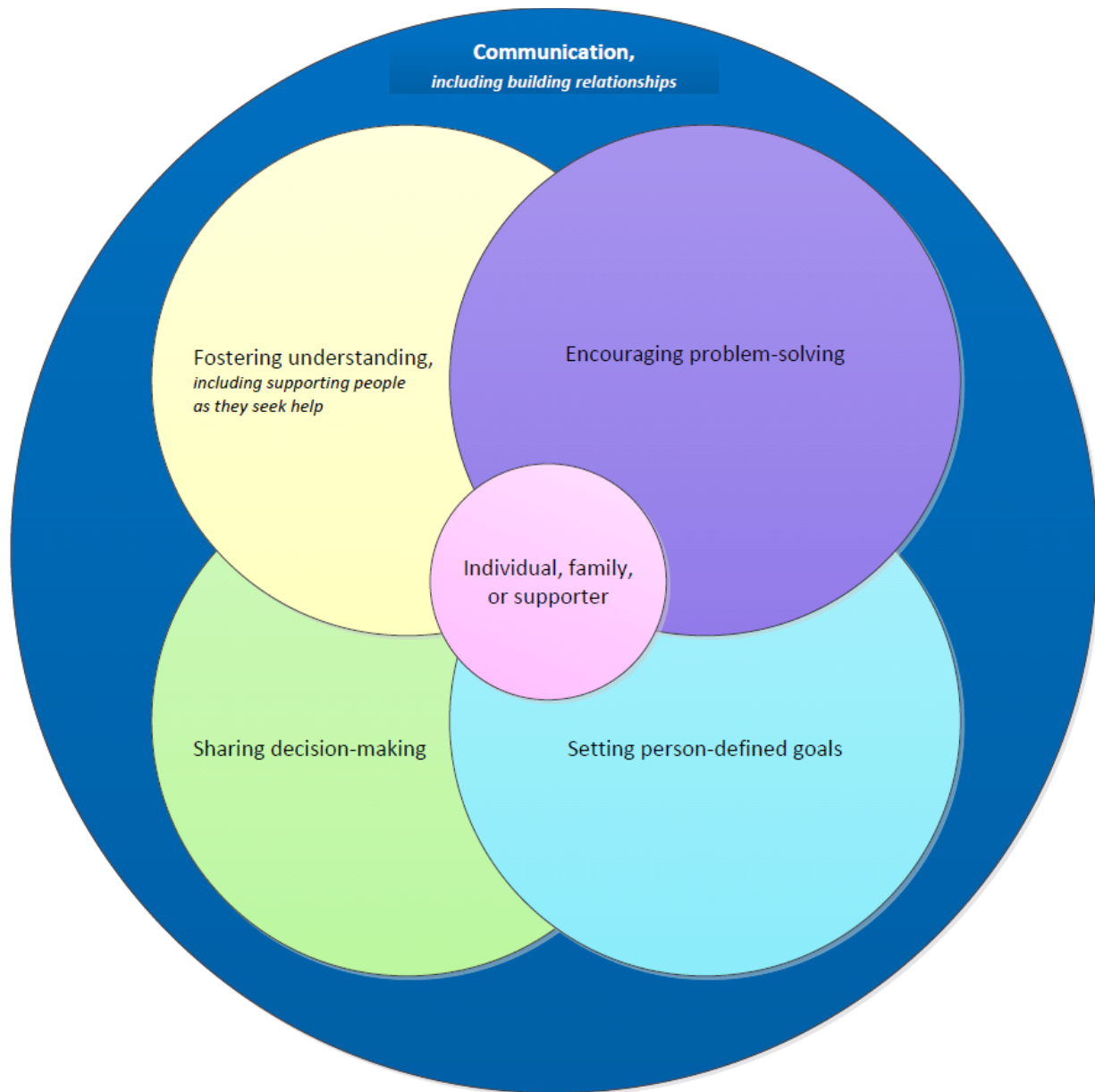


Figure 4. Relationship of themes identified in review of person-centered approach to nursing practice with respect to self-care in a Heart Function Clinic



Heart Failure Zones

Check Weight Daily

- ♥ Weigh yourself in the morning before breakfast. Write it down. Compare your weight today to your weight yesterday.
- ♥ Keep the total amount of fluids you drink to only 6 to 8 glasses each day. (6-8 glasses equals 1500-2000 mL or 48-64 oz)
- ♥ Take your medicine exactly how your doctor said.
- ♥ Check for swelling in your feet, ankles, legs, and stomach.
- ♥ Eat foods that are low in salt or salt-free.
- ♥ Balance activity and rest periods.



Which Heart Failure Zone Are You Today? Green, Yellow, or Red

Safe Zone

ALL CLEAR – This zone is your goal!
Your symptoms are under control.

You have:

- No shortness of breath.
- No chest discomfort, pressure, or pain.
- No swelling or increase in swelling of your feet, ankles, legs, or stomach.
- No weight gain of more than 4 lbs (2 kg) in 2 days in a row or 5 lbs (2.5 kg) in 1 week.



Caution Zone

CAUTION – This zone is a warning

Call your Health Care provider (eg. Doctor, nurse) if you have any of the following:

- ▲ You gain more than 4 lbs (2 kg) in 2 days in a row or 5 lbs (2.5 kg) in 1 week.
- ▲ You have vomiting and/or diarrhea that lasts more than two days.
- ▲ You feel more short of breath than usual.
- ▲ You have increased swelling in your feet, ankles, legs, or stomach.
- ▲ You have a dry hacking cough.
- ▲ You feel more tired and don't have the energy to do daily activities.
- ▲ You feel lightheaded or dizzy, and this is new for you.
- ▲ You feel uneasy, like something does not feel right.
- ▲ You find it harder for you to breathe when you are lying down.
- ▲ You find it easier to sleep by adding pillows or sitting up in a chair.



Health Care Provider _____ Office Phone Number _____

Danger Zone

EMERGENCY – This zone means act fast

Go to emergency room or call 911 if you have any of the following:

- You are struggling to breathe.
- Your shortness of breath does not go away while sitting still.
- You have a fast heartbeat that does not slow down when you rest.
- You have chest pain that does not go away with rest or with medicine.
- You are having trouble thinking clearly or are feeling confused.
- You have fainted.



The information in this document is intended solely for the person to whom it was given by the healthcare team.
For more information refer to: www.bcheartfailure.ca

Figure 5: Heart Failure Zones (Provincial HF Network, 2013b)

Appendix A

JHNEBP Research Evidence Appraisal

Evidence Level: _____

ARTICLE TITLE:				NUMBER:	
AUTHOR(S):				DATE:	
JOURNAL:					
SETTING:			SAMPLE (COMPOSITION/SIZE)		
<input type="checkbox"/> Experimental	<input type="checkbox"/> Meta-analysis	<input type="checkbox"/> Quasi-experimental	<input type="checkbox"/> Non-experimental	<input type="checkbox"/> Qualitative	<input type="checkbox"/> Meta-synthesis
Does this study apply to my patient population?				<input type="checkbox"/> Yes	<input type="checkbox"/> No
If the answer is No, STOP here (unless there are similar characteristics).					
Strength of Study Design					
<ul style="list-style-type: none"> • Was sample size adequate and appropriate? • Were study participants randomized? • Was there an intervention? • Was there a control group? • If there was more than one group, were groups equally treated, except for the intervention? • Was there adequate description of the data collection methods 				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
Study Results					
<ul style="list-style-type: none"> • Were results clearly presented? • Was an interpretation/analysis provided? 				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
Study Conclusions					
<ul style="list-style-type: none"> • Were conclusions based on clearly presented results? • Were study limitations identified and discussed? 				<input type="checkbox"/> Yes	<input type="checkbox"/> No
				<input type="checkbox"/> Yes	<input type="checkbox"/> No
PERTINENT STUDY FINDINGS AND RECOMMENDATIONS					
Will the results help me in caring for my patients?				<input type="checkbox"/> Yes	<input type="checkbox"/> No

Evidence Rating (scales on back)

Strength of Evidence Rating			
Quality Rating (check one)	<input type="checkbox"/> High (A)	<input type="checkbox"/> Good (B)	<input type="checkbox"/> Low/major flaws(C)

Appendix B

JHNEBP Non-Research Evidence Appraisal

Evidence Level: _____

ARTICLE TITLE:		NUMBER:	
AUTHOR(S):		DATE:	
JOURNAL:			
<input type="checkbox"/> Systematic Review	<input type="checkbox"/> Clinical Practice Guidelines	<input type="checkbox"/> Organizational (QI, financial data)	<input type="checkbox"/> Expert opinion, case study, literature review
Does review/expert opinion address my practice question?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
If the answer is No, STOP here (unless there are similar characteristics).			
Systematic Review			
• Is the question clear?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are search strategies specified, and reproducible?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are search strategies appropriate to include all pertinent studies?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are criteria for inclusion and exclusion of studies specified?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are details of included studies (design, methods, analysis) presented?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are methodological limitations disclosed?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are the variables in the studies reviewed similar, so that studies can be combined?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Clinical Practice Guidelines			
• Were appropriate stakeholders involved in the development of this guideline?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are groups to which guidelines apply and do not apply clearly stated?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Have potential biases been eliminated?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Were guidelines valid (reproducible search, expert consensus, independent review, current, and level of supporting evidence identified for each recommendation)?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are recommendations clear?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Organizational Experience			
• Was the aim of the project clearly stated?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Is the setting similar to setting of interest?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Was the method adequately described?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Were measures identified?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Were results adequately described?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Was interpretation clear and appropriate?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Individual expert opinion, case study, literature review			
• Was evidence based on the opinion of an individual?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Is the individual and expert on the topic?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Is author's opinion based on scientific evidence?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Is the author's opinion clearly stated?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
• Are potential biases acknowledged?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
PERTINENT CONCLUSIONS AND RECOMMENDATIONS			
Were conclusions based on the evidence presented?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Will the results help me in caring for my patients?		<input type="checkbox"/> Yes	<input type="checkbox"/> No

Quality Rating (scale on back):

Basic quality rating of the study under review (check one)	<input type="checkbox"/> High (A)	<input type="checkbox"/> Good (B)	<input type="checkbox"/> Low/major flaws(C)
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