Enhancing Outpatient Heart Failure Self-care Through Health Literacy and Cultural Sensitivity

by

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RN, BCIT, 1998
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Abstract

In this paper, I present an integrative literature review to explore whether health literacy (HL) and cultural sensitivity can strengthen nurses' capacity to foster self-care in outpatient heart failure disease management programs (HFDMPs), and to enable sustainable health outcomes for adult HF patients. Literature from nursing, medicine, psychology, and social sciences is synthesized to develop the concepts of self-care, HL, and cultural sensitivity using the exemplar of outpatient adult HF care, in British Columbia (B.C.). Adults with HF cared for in outpatient clinics can be intimidated by generalized, evidence-driven self-care prescriptions, particularly if they do not fully understand the nature of their heart disease, its implications, or how certain therapies can control symptoms, delay disease progression and preserve quality of life (QOL). Health care providers can enhance the outpatient HF self-care experience using a holistic-biomedical perspective which draws on principles of Orem's Self Care Deficit Theory (SCDT), HL, and cultural sensitivity. Future research should evaluate HFDMPs that include attention to HL and cultural sensitivity to determine if such enhanced programs enable sustainable patient improvements in HF symptoms and QOL, and if these improvements can occur sooner and with greater impact when HL and cultural sensitivity are integrated into HF self-care guidelines in an outpatient program.

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List of Abbreviations

Abbreviation	Definition
ASKED	Awareness, Skill, Knowledge, Encounter, Desire -the five constructs of the Process of Cultural Competence
CCS	Canadian Cardiovascular Society
DHFKS	Dutch heart failure knowledge scale
HF	heart failure
HFDMP	heart failure disease management program
HL	health literacy
IOM	Institute of Medicine
NTL	no time limit
NVS	newest vital sign
PCC	Process of Cultural Competence
QOL	quality of life
REALM	Rapid Estimate of Adult Literacy in Medicine
SCDT	Self-care Deficit Theory
SCHFI	self-care of heart failure index
S-TOFHLA	Short Form Test of Functional Health Literacy
TOFHLA	Test of Functional Health Literacy

Statement of the Problem

People living with heart failure (HF) experience a reduced quality of life (QOL) and exacerbated episodes of increased shortness of breath, chest pain, fatigue, weakness, rhythm disturbances, and feeling unwell that makes them seek urgent medical attention and often hospitalization (Bostock, 2011, Britz & Dunn, 2010; Cameron, Worrall-Carter, Driscoll, & Stewart, 2009; Chen, Yehle, Plake, Murawski, & Mason, 2011). HF occurs when the heart muscle weakens and over time is unable to pump blood adequately to meet the nutritional needs of body tissues and organ systems. HF is a condition known to stem from ischemic (coronary artery disease) and non-ischemic (congenital, structural heart disease, chemotherapy, alcohol abuse-related) origins. It occurs in young and old adult populations and can become a chronic disease just like diabetes, chronic obstructive lung disease, cancer and others, leading to increased medical office visits, emergency room visits, and extensive time spent in hospital. HF is known to remodel the heart muscle and gradually alter its size, structure, and function, if left untreated or poorly managed. Over time, the stress of poor blood flow due to reduced pumping action of the heart muscle can cause other organ systems to become compromised and dysfunctional.

Changes in heart function are associated with a constellation of HF symptoms and presentations that are expensive to treat, debilitating for patients and their families, and clinically challenging for providers to manage. Healthcare providers find progressive HF creates a ‘revolving door’ effect where patients return repeatedly to hospital with acute exacerbations of a disease condition that could be stabilized at home through education and self-care by the patient (Boyde, et al., 2009; Britz & Dunn, 2010; Cameron, Worrall-

Carter, Driscoll, & Stewart, 2009; Chaudry, et al., 2011; Chen, et al., 2011; Davidson, MacDonald, Moser, Ang, et al., 2007).

People living with HF can experience difficulty with normal work and activity and this can lead them to feel marginalized as a burden to family, friends, and society. The government of Canada recognizes that the country faces an increasing population of chronic disease sufferers over the coming years. Medical science provides early detection and a variety of treatment options for chronic conditions like HF, and this enables Canadians to experience an increase in survival rates and improvements to QOL. Canadians can expect to be active, productive members of society to the extent they want to be, even though they may be medically classified as having HF.

In an effort to ensure that citizens are being educated and treated with current Canadian Cardiovascular Society HF guidelines, the provincial government's strategy is to establish outpatient HF networks whereby people can receive self-care education, evidence-driven treatment, and surveillance of their HF condition in a standardized and systematic way (B.C.'s Heart Failure Network, 2012). The provincial HF strategy aims to educate people to understand disease presentations and progressions in order to impact population health upstream by enabling people with HF through self-care to recognize and reduce symptoms and therefore play an important role in reversing underlying HF dysfunction. Part of the strategy involves patients learning to develop and sustain self-care skills in partnership with dedicated health care providers on an outpatient basis (BC HF Network, 2012).

The use of evidence-driven guidelines to standardize and support HF treatment is important for patients, HF service providers, and health care systems. The Canadian Cardiovascular Society (CCS) HF guidelines are “part of a commitment to a multiyear initiative to provide support for the best practice of HF management” (Howlett, et al., 2010, p. 185). CCS uses a “systematic review strategy and methods for formulating recommendations” (p.185) to provide consensus guidelines for practitioners. Evidence-informed guidelines lend credibility to care practices that emerge and provide a point of reference for patients and providers regarding treatment protocols. However, there is a lack of evidence for how providers ought to view and support diverse groups of HF patients towards integrating HF therapies into their daily lives despite variable HL levels, and cultural challenges, (Heydari, Ahrari, & Vaghee, 2011; Manning, Wendler, & Baur, 2010). Evidence-driven approaches for integrating guidelines into outpatient self- care are needed.

There is a risk providers could develop ineffective communication styles and clinical behaviours when implementing guideline-driven therapies, in a fast-paced environment. Providers must be careful not to assume that HF self-care guidelines can be easily taught and adopted by every HF patient that comes into a busy, tightly-scheduled clinic. Members of the HF community come from different backgrounds and some speak English as a second language whereas others do not speak English at all. These types of patient encounters necessitate the need for extra time and care to assess the patient and tailor HF self-care teaching adequately. Some patients are disadvantaged by health literacy (HL) deficits which pose barriers to maintaining a HF self-care plan that can

provide stability and prevent symptom exacerbations. Others may hold culturally ingrained values about health or illness that can confound their self-care practices. Providers, themselves can slip into performing routine clinic work for the sake of keeping to a schedule, without carefully assessing and addressing HF patients' self-care needs as well as concerns of family members or significant others.

When patients visit outpatient HF clinics, they are subjected to routine questions, blood pressure, body weight, and electrocardiography measurements including a physical exam either by a Nurse Practitioner or a Cardiologist. Patients can expect to receive counselling from a Dietitian, a Pharmacist, or a Social Worker. The outpatient HF clinic can be a hurried and demanding environment in which patients and providers are supposed to connect over HF issues that affect patients' QOL. In this paper, I will examine the notions of HL and cultural sensitivity as underpinnings for enhancing HF self-care and associated patient-provider partnerships in an outpatient setting. Generally speaking, it is unusual for providers to encounter patients who are always capable of recognizing and responding to their HF symptoms effectively. This is especially true when patients are elderly, non-English speaking, awkward with health information and self-monitoring concepts, reside in remote or under-serviced areas and live with other chronic conditions (Heydari, et al, 2011; Kaan, 2005; Seto, et al., 2011). A coordinated approach to HF management in B.C. is still relatively new and has yet to prove that access to outpatient HF care and services with standardized protocols and education are leading to long term benefits for patients, providers, and health care systems.

In B.C., there are more than 90,000 individuals living with HF, and by 2030 this number is expected to double (BC Heart Failure Network, 2012). The economic burden of this disease felt by the provincial government has resulted in an adult outpatient HF ‘hub and spoke’ strategy that is expected to be adopted throughout the geographical expanse of BC and among its diverse HF patient population (Boyde, et al., 2009). This strategy assumes that health care professionals will be able to effectively deliver HF disease management programs (HFDMPs) governed by evidence-driven guidelines.

The HFDMP is meant to be a six to nine month period in which HF self-care can be systematically assessed and strengthened. HF outpatients are informed of medical therapies supported by current evidence and how these therapies can be integrated into personal HF self-care, on a daily basis. Part of the HFDMP is a surveillance strategy whereby special tests are scheduled to assess if patients’ hearts are responding to medication, diet, and exercise.

The provincial HF strategy is shifting HF care from one that is reactive by the healthcare system to one that is proactive by the patient (Britz & Dunn, 2010). Adult HF outpatient programs are meant to establish self-care confidence in patients so they can perform changes in personal health care behaviours that can slow down or reverse deterioration of the heart muscle over time. Patients with heart disease can achieve an improved sense of well-being over a six to nine month period and experience less need for urgent medical or hospital visits which further improves their QOL (Langer, 2008). However many people living with HF are accustomed to a paternalistic health care system telling them what to do. It is unrealistic to expect all HF outpatients to participate

in a HFDMP willingly and easily. As providers we have to encourage and support a shift from the paternalistic medical model towards a social model in which patients can feel in control, capable, and ready to participate in learning about HF and self-adjusting their medication, diet, and lifestyle behaviours.

The current goals of the HFDMPs do not encompass attention to HL and cultural sensitivity. Given my experience of caring for the HF population, I contend that HFDMPs would be strengthened by attending to HL, cultural sensitivity, unique end of life concerns and the socio-political, economic and geographic contexts unique to each person within the HF patient population. HL and cultural sensitivity are two constructs that will be explored in this paper towards offering clinical insights and practical tips from the literature that providers can draw from when working with HF patients, especially on an outpatient basis. In outpatient settings, providers are positioned to guide patients to embark on the necessary self-care journey that could help slow down or reverse their heart dysfunction towards healthier parameters. Providers can optimize outpatient care by consistently practicing and adjusting simple approaches for assessing and supporting patients' self-care behaviours. As providers we need to concern ourselves with HL and cultural sensitivity issues in order to make an impressionable impact at point of care delivery so patients and their significant others can grasp health-related messages for post-clinic reflection and action.

Literature Review Methodology

In this paper, Whittemore and Knafl's (2005) integrative literature review methodology is used to align HL and cultural sensitivity with the HF self-care paradigm

in outpatient HF disease management programs (HFDMPs). According to Whittemore and Knafl, integrative reviews can combine experimental and non-experimental findings to inform evidence-based practice. An integrative literature review was undertaken because this approach uses a broad range of information sources and methodologies to uncover existing knowledge and ideas about a topic of interest. The advantage of using diverse research methodologies to inform professional practice is that the knowledge generated is not solely reliant on any particular type and source of evidence (Whittemore & Knafl, 2005); especially given that information on HL and cultural sensitivity in the background of outpatient HF care is limited. In a mixed methodology design, an integrative review can offer a blend of critical information for knowledge-seekers to mitigate gaps in clinical practice The mixed methodology or hybrid of experiential and experimental evidence fits the purpose of this paper which merges a holistic paradigm (experientially-informed) combined with a biomedical (experimentally-informed) paradigm for enhancing outpatient HF self-care.

Based on Whittemore and Knafl (2005), a five step process is used to examine the literature for evidence that supports a holistic-biomedical model of HF self-care. The five step process consists of: 1) Problem identification, 2) literature search, 3) data evaluation, 4) data analysis, and 5) presentation. A "methodologic matrix" as outlined in chapter five of Polit and Beck (2008) is used to organize and evaluate literature sources in terms of research methodologies used in the articles and reports found. Each report is given a "high", "medium", or "low" rating in terms of usefulness in providing valid information for the construct of a holistic-biomedical paradigm that can inform standard

HF care practices in outpatient HFDMPs. High-rated reports demonstrate methodological or theoretical quality, and informational value (Whittemore & Knafl, 2005).

The literature search for this paper considers self-care, HL, and cultural sensitivity as independent variables of interest and outcomes of adult HF self-care as a dependent variable. Searches in the following computerized databases: CINAHL, MEDLINE, PsycInfo, and EBSCO make use of the following key words "HF, adult HF care, self-care, HL, HL and HF, self-care and HF, self-care deficit theory, cultural sensitivity, ethnicity and HF". Ancestry searches using references found within literature are included. Literature sources include peer reviewed journals and published research reports written in English, and the provincial HF website. Articles between 2005 and 2012 on self-care, HL, and cultural sensitivity are reviewed, including a few earlier papers (2001, 2003, and 2004) on cultural sensitivity which give insights useful to the construct put forward in this paper. International research papers (written in English) are included to bring in multicultural perspectives, and grey literature is not used.

Articles were read two or three times for relevance and fit into building a holistic-biomedical perspective for outpatient HF self-care. The first and second critical readings assigned a rating of high, medium, or low with margin notes and highlighting of key sections. Annotated bibliographies were written for articles used in this paper, which sometimes required a third reading. Annotated bibliographies were grouped into categories of HF self-care, HL, and cultural sensitivity and used in writing the body of

this paper. The methodological matrix can be found in Appendix A. Primary and secondary validity criteria against which reports were rated is shown in Appendix B.

Scope of the Project

The literature review for this project examines HL and cultural sensitivity challenges to outpatient HFDMPs in terms of implementing and sustaining effective outpatient HF self-care programs. In a culturally diverse province, it is yet to be determined if positive, long term changes to HF disease progression are achievable and sustainable through outpatient HF self-care programs. Outpatient HF self-care is supposed to offset conventional inpatient HF management by reserving vital health care resources for moments when patients experience debilitating episodes of breathing difficulties, fluid accumulation in the body, crippling fatigue, and significant problems in coping with activities of daily living (Barnason, Zimmerman, &Young, 2011; Britz & Dunn, 2010; Heydari, et al., 2011; Seto, et al., 2011; Tierney, et al., 2011).

Patient-provider partnerships in the outpatient setting are integral to the success of HFDMPs being able to offset the burden of inpatient care. Getting patients of a diverse adult cardiac outpatient population to integrate Western guideline-driven HF self-care into their daily lives can present challenges. Offering outpatients a HFDMP that delivers biomedical guidelines in a manner that meets HL and cultural sensitivity needs can serve to keep HF patient populations out of hospital and enjoy a more productive life. As part of clinical practice in outpatient settings, providers are positioned to support patients in engaging in self-care, guiding them towards self-care behaviours and participating in a self-care culture (Cross, 2011). Exploration into self-care, cultural sensitivity, and HL

reveal insights that could support future integration of these concepts into HFDMPs. Findings from this paper offer insights and background knowledge to help evolve how providers ought to view and support all HF patients' experiences with integrating guideline-driven therapies into their daily lives (Anderson, et al., 2003; Baker, 2006; Barnason, et al, 2011; Britz & Dunn, 2010; Heydari, et al., 2011; Seto, et al., 2011; Tierney, et al., 2011).

Learning from the Literature

Salient features of outpatient HF self-care concepts emerge out of the literature for this project. These features include: heart failure disease management programs (HFDMP); self-care culture; Self-care Deficit Theory (SCDT); and Self-care in Heart Failure Index (SCHFI) which are presented below.

Heart Failure Disease Management Program

HFDMP designs provide a systematic approach to applying evidence-informed guide-lines (Herbert, et al., 2010). A typical HFDMP consists of visits to an outpatient clinic setting at three-month intervals (or more frequently, if needed). During these visits and depending on the nature of the visit the patient may see a cardiologist a Nurse Practitioner, a clinic nurse, a pharmacist and/or a dietitian. The patient receives "standardized" HF self-care education about medications, diet, and exercise. Ongoing information sharing about HF therapies occur, and clinical and biochemical measurements such as blood pressure, heart rate, heart rhythm, oxygen saturation, weight, body mass index, electrolytes, complete blood counts, and echocardiograms are done, as needed (Herbert, et al., 2010). Patients are expected to report on their symptoms, self-

care skills, and other HF concerns. Two important variables that providers use to track patients' treatment response and disease progression are the New York Heart Association (NYHA) classification of functional limitation due to HF and the heart's ejection fraction, which is an estimate of the amount of blood pumped out of the heart with every contraction of the left ventricle (Herbert, et al., 2010).

Self-care Culture

Creating a self-care culture imposes a departure from traditional expectations of "instant fixes". "We need to see a shift in language [and clinical behaviours] away from things being done 'to' patients to ways of working 'with' our patients", (Cross, 2011, p.18). Over time the benefits of self-care for patients can mean less anxiety, depression, and tiredness; while a sense of well-being increases, self-efficacy develops, and QOL improves (Cross, 2011). Increased life expectancy, fewer hospital visits, shorter hospital stays, less follow-up appointments, medication, and fewer days off work can also be realized (Cross, 2011). Patients can exercise self-agency over their HF condition and learn to be better self-advocates in bringing HF issues to their interdisciplinary teams, knowing they will have opportunity to have their voices heard.

Good self-care by patients can benefit health care systems by cutting down service costs. A comprehensive self-care program can inform patients of the appropriate action to take when faced with HF symptoms or exacerbations. Meanwhile, it is important for nurses in outpatient settings to remember that 'self-care' is not the same as 'no care' while patients take time to build their self-care confidence. There will be times when seeking provider attention is the appropriate action for patients to take. Good self-care

means patients can interpret their body signals and confidently apply treatment steps to reduce symptoms and maintain a stable state (Cross, 2011). HF patients who can function cognitively well can learn to recognize personal trends in their symptoms and body responses which can reduce uncertainties and increase self-awareness and self-confidence in knowing what to do at an early symptom phase before a situation becomes unmanageable. One theoretical basis for care delivery that HFDMPs can integrate in outpatient settings is the Self-care Deficit Theory (SCDT) which can guide providers in helping patients commit to self-care practices.

Self Care Deficit Theory

The Self-care Deficit Theory (SCDT) is a conceptual construct for nursing practice put forward in the 1950's by Dorothea Orem. The theory has come under criticism for its complex language and construction making it challenging to understand and apply to contemporary nursing practices. Nursing theories like the SCDT offer a framework for nursing work and help prevent the risk of nursing being reduced "…to the domain of the common-sense" (Timmins & Horan, 2007, p.33). The SCDT frames an ideology of patients' own self-care that outpatient HFDMPs can promote. Changes in health care economics have engendered the emergence of self-care along with concepts of QOL, health promotion, patient-focused care, empowerment, support and education forming an ontological basis for contemporary philosophies of nursing practice for health conditions such as HF (Timmins & Horan, 2007). Rising health care costs tend to move society away from expecting traditional inpatient health services to accepting out-patient management of stable chronic disease conditions like HF. Emphasis is placed on

developing self-care support structures, keeping patients out of hospital, and reducing lengths of hospital stays. As a result, health care professionals experience a shift in the way they think about patient care and clinical practice. The SCDT provides a conceptual framework for nursing action that can be used with adult HF outpatients who are not in acute care settings. If successfully applied to contemporary nurse-led HF self-care monitoring programs in outpatient settings, the SCDT could engender redesigns of how nurses participate in partnerships with patients in non-acute settings. For nurses in these settings, a balance needs to be found to enable holistic care practices with HF patients, while at the same time promoting evidence-informed pathways of HF care. The SCDT suggests that HF patients can be helped to effectively realize their self-care agency or the “ability to act deliberately” (p.33) in the face of HF over time, provided they can draw on internal and external resources. Internal resources would be self-awareness, self-confidence, and acquired knowledge; external resources would be updated knowledge and supportive insights from health resources such as health care providers.

Nurses in outpatient settings can be instrumental in helping to organize the internal and external environments that HF patients can draw from as they go about their day to day living. In outpatient settings, nurses are positioned to pre-empt patients’ self- care deficits by recognizing and urgently intervening if patients’ care needs begin to exceed their individual ability to meet those needs. According to the SCDT, nursing agency (deliberate action taken by nurses) can shift from being completely compensatory to partially compensatory to supportive and educative according to patients’ HF needs (Timmins & Horan, 2007). Nurses still have to critically assess HF patients in an

outpatient setting, and assist patients without compromising their self-care abilities. The SCDT suits contemporary HF nursing philosophies of encouraging patients' abilities for self-care. The SCDT could be used to develop modern cardiac nursing education programs, newer models of cardiac care and develop interventions geared towards improved self-care abilities of patients (Timmins & Horan, 2007). As self-care becomes more main stream, especially in HF, it will be helpful to have a means of evaluating patients' perceived efficacy of HF self-care and provide further support to sustain this type of care. The Self-care of HF Index explored in the next section is a tool that can be used for evaluating a HFDMP based on self-care.

Self-care of Heart Failure Index

It is said that "the foundation of all rigorous research designs is the use of measurement tools that are psychometrically sound" (DeVon, et al., 2007, p.155), and that confirmation of validity and reliability of tools assures us of the integrity of study findings. The Self-care of HF Index (SCHFI), first published in 2004, is a scale that is often referred to in HF literature and used as a measurement tool for self-care related to HF. The scale has gained global recognition in twenty-five countries and has been used in more than seventeen published studies. The SCHFI has undergone reassessment for internal validity by quantitative and qualitative means (Riegel, Lee, Dickson, & Carlson, 2009). The background for constructing the scale begins with how self-care is defined by its primary author Riegel and a team of colleagues.

In the view of these scholars, self-care is a 'naturalistic decision-making process' that involves the choices of self-maintenance and self-management behaviours that are

enacted with varying degrees of self-confidence. Self-maintenance involves the acts of measuring daily weights, checking blood pressure readings, watching salt and fluid intake, taking prescribed HF medication constitute self-maintenance behaviours that HF patients perform to ensure heart function stability (Barnason, et al, 2011; Heydari, et al, 2011; Seto et al, 2011; Tierney et al, 2011; Britz & Dunn, 2010). Self-management behaviours involve in-the-moment active deliberate decision-making about how to deal with symptoms of unstable heart function. It requires recognizing when symptoms are serious enough to take evasive action with a decisive treatment strategy and being able to evaluate the outcome of that strategy (Cameron, et al., 2009; Riegel et al, 2009). Self-confidence is a personal characteristic that affects an individual’s ability to take deliberate actions in the self-maintenance and self-management phases. Self-confidence plays an important role between HF self-care and health outcomes. The authors feel that confidence measures make the SCHFI adaptable to both symptomatic and asymptomatic HF patients. Investigators can use the same scale for symptom-free HF patients to collect self-care maintenance and confidence scores while both these scores and the self-management score can be applied to HF patients who have had symptoms (Riegel et al, 2009). In other words, the SCHFI is adaptable to the HF patient situation making it an easy, convenient measurement tool for providers to apply in a HF patient population.

The SCHFI is essentially three scales in one that weighs three self-care processes: self-maintenance, self management, and self-confidence. Each subscale consists of questions that are answered on a four-point Likert scale (Seto, et al, 2011; Riegel, et al, 2009). Over the years as HF knowledge has evolved the self-maintenance scale of the

SCHFI has been revised to appropriately reflect changes in HF therapies. The SCHFI collects empirical as well as experiential data, each subscale score totals to 100 for easier inter-scale comparisons and overall interpretation (Riegel et al, 2009). In research, scales such as the SCHFI are evaluated for internal consistency using the widely accepted Cronbach's alpha method, which is a complicated formulation and not within the scope of this paper's discussion. The Cronbach alpha value can range "between 0.00 and 1.00 and high values reflect a higher internal consistency" (Polit & Beck, 2008, p.455). Cronbach's alpha for the SCHFI indicates the extent to which internal consistency exists overall in its subscales to report reliable scores related to the self-care phenomenon.

Cameron et al. (2009) reviewed twenty-one HF disease-specific self-care measurement tools and found only two that enhance their credibility by reporting reliability and validity. The two measurement tools are the European HF Self-care Behavior Scale and the SCHFI, and out of the two the SCHFI has gained the most credibility. The authors mention that in the original 2004 version of the SCHFI, Riegel et al reported a Cronbach alpha of 0.76 as an overall validity score. In a 2009 update on the SCHFI put forward by Riegel and colleagues, the authors move away from a total SCHFI score assessment and recommend instead that each of the subscales be measured separately. Evolution in the concept of HF self-care views self-confidence as a mitigating factor in the relationship between self-care and HF outcomes (Cameron et al, 2009; Riegel et al, 2009). Between the two versions of the SCHFI, internal consistency was 'satisfactory' for the self-management subscale with "Cronbach alpha, 0.70 and 0.60, respectively" (Cameron et al, 2009, p.E14) and 'good' for the self-confidence subscale

with “Cronbach alpha, 0.82 and 0.83, respectively” (p.E14). The self-maintenance subscale has produced low internal consistency with “Cronbach alpha, 0.56 and 0.55” (p.E14) in both SCHFI versions. The authors explain this as an expected trend because self-maintenance can be “influenced by many factors other than HF” (Cameron et al, 2009, p. E14) and can “reflect the wide variety of therapeutic and lifestyle behaviours” (Riegel et al, 2009, p. 486) that HF patients participate in. The use of the SCHFI shows that individual responses between sub-scales can vary indicating no significant inter-correlations which indicates that each sub-scale measures different self-care constructs, and avoids redundancy.

The SCHFI demonstrates stability in terms of its test-retest reliability after being repeatedly used at monthly intervals with the same HF patient sample. Results did not reveal a dramatic improvement in self-care scores as would be expected if a patient sample learns from the SCHFI questions, over time (Cameron et al, 2009; Riegel et al, 2009). Finally, the SCHFI has also been assessed in terms of ‘social desirability’ of responses – that is patients responding to questions in a manner they feel would meet social approval rather than reflecting their personal reality. Out of the three subscales, the confidence scale is vulnerable to social bias which can influence patients’ responses in certain populations. This presupposes the utility of cultural sensitivity when interfacing with HF patients of different cultures. Patients from different cultural backgrounds can sometimes perceive a need to alter their personal narratives to conform to versions that are socially acceptable by others in their cultural communities and within their own families. Self-reporting is a delicate means of data collection especially for HF

patients who have to take stock of their QOL and coping skills and perceived mortality. Investigators and health care providers have to rely on self-reporting by HF patients to grasp the meaning of self-care as experienced by the patient. Providers must remain intuitive to the risk of over or underestimated self-reported data from patients' self-assessments of their HF condition (Cameron et al, 2009; Polit & Beck, 2008; Riegel, et al, 2009).

The SCHFI uses a score of 70 (out of 100) and greater as an indicator of adequate self-care. HF clinics strive to help patients improve their baseline heart function by embarking on an informed self-care program. Four outcomes of HF, (perceived improvements, reduced mortality, reduced hospital visits, and no hospital visits) are used as goal-setters in HF self-care, and the effectiveness of self-care is judged based on the outcome of interest that a patient strives for through their own self-care agency (Riegel et al, 2009). For example with some patients it is more important to perceive improvement in overall symptoms and level of function before reducing hospital visits. Potential outcome-driven adequacies of HF function that can be captured by SCHFI scores and compared over time through repeat testing are summarized in Table 1.

Table 1 Potential Outcomes indicated by Self-care in HF Index Scores

SCHFI score out of 100	Outcome of interest
15	Start to see improvements in perceived health status
50	Reduced mortality and hospital visits
75	Reduced hospital visits
90	No hospital visits, health perceived as better than general HF population.

(Adapted from Riegel et al, 2009, p. 492)

Updates to the SCHFI by its original authors, indicates a commitment to ensuring a tool that stays current with HF, and self-care knowledge. Efforts have been made to adjust and strengthen the internal consistency of the self-maintenance subscale based on current practices. An assumption is that by nature, HF self-care measurement strategies and their outcomes are challenging to measure. HF patients face the challenge of accurately communicating their self-care experience in standard terms or clear language that can be understood by healthcare providers and investigators. Given variable HL levels prevalent among HF outpatients, these patients also face the challenges of understanding their condition, its signs and symptoms of progression, the reasoning behind treatment strategies, and performing lifestyle changes encouraged in a self-care program. HF patients' general sense of well-being will also factor into their ability to give accurate self-reports at any point in their HF journey. The SCHFI continues to gain credibility in its utility as a standard of measure for HF self-care assisting in evaluating the impact of patient education strategies used in HF outpatient settings. Opportunities for ongoing use and development could potentially see the SCHFI becoming the "gold standard" measure of HF self-care. The utility of this tool can expand into predicting relationships between self-care behaviours and HF outcomes. HFDMPs in BC can confidently use the SCHFI to measure changes in outpatients' self-care behaviours.

Delivery of Outpatient Heart Failure Self-care

In an integrative literature review Barnason, Zimmerman, and Young (2011) use Whittemore and Knafl's (2005) methodology, to examine nineteen studies about specific patient education interventions used to impact HF self-care. This review confirms that

even with medical advances in HF, patients living with this condition still cannot experience improved QOL and optimal outcomes, unless “cognitive behavioral strategies” are used to enhance their self-care. Multiple theories exist in the literature examined by the authors around the concepts of self-care and HL. Barnason, et al., (2011), view HF self-care as a necessary means for people living with HF to experience improved QOL outcomes. In order to do this, HF outpatients have to be able to optimize self-care therapies on their own within the context of their lives and in multiple environments. The authors describe HF self-care as consisting of maintenance and management behaviours. In their view, self-care maintenance involves recognizing and interpreting HF symptoms in order to intervene appropriately when they occur. Specific self-care maintenance behaviours include taking daily weights, monitoring signs of fluid accumulation in the body, exercising, using less salt, and following medication prescriptions (Barnason et al, 2011; Britz & Dunn, 2010; Cameron, et al, 2009; Chaudhry, et al., 2011). Review of the literature finds that not many studies have thoroughly examined HF self-care and health outcomes for patients, yet there is a perception of reduced hospital visits among patients who can recognize and self-treat their symptoms appropriately (Barnason, et al., 2011).

Patient characteristics known to hinder self-care abilities include mental health weaknesses, advanced HF conditions, concomitant chronic conditions, inadequate HL levels, and having little experience with the health care system (Barnason, et al., 2011). Optimal self-care can be realized if the patient has social or familial support networks, a HF condition that is not too far advanced, functional levels of mental and physical

abilities, higher education, and not feeling intimidated by health care systems (Barnason, et al., 2011). Despite the low ethnic diversity among study samples in the literature review by Barnason, et al., (2011), there are useful insights that support focused education interventions for an adult HF patient population. The inclusion criterion in the literature review requires reports to have intervention and control groups in their study designs. The review uses a systematic data collection methodology to summarize and present key characteristics of effective HF education interventions. Education interventions like one-on-one or group counseling, video conferences, and telehealth can be helpful for delivering HF self-care knowledge to outpatients. Intervention deliveries can occur daily, weekly, and monthly over three to six months. Furthermore, realistic and attainable self-care goals support building positive self-concepts in the context of HF. Support groups or significant others can strengthen patients' self-concepts by encouraging patients' sense of autonomy in their self-care (Barnason et al, 2011).

Through effective self-care, HF patients are able to develop positive self-concepts despite living with a life altering chronic heart condition. Self-concept is defined as the ''beliefs and feelings about oneself at a given time" (Heydari, et al., 2011, p. 476). Self-concept forms out of our ''internal perceptions and perceptions from others' reactions [to us]" (Heydari et al., 2011, p. 476). Furthermore, self-concept "plays a major role in directing the individual's behavior [or self-agency]" (Heydari et al., 2011, p. 476). Self-concept (knowing oneself) and self-efficacy (belief in being able to do something) are driven by individual internal and external factors (Heydari, et al., 2011; Tierney, et al., 2011). Theoretically, in order to enact self-efficacy in HF self-care successfully, a patient

must have a strong self-concept. It is important to give attention to the HF patient's internal environment around how they feel and view themselves because this can influence patients' willingness to participate in self-care activities. Strong skills in dealing with cultural sensitivity and HL inadequacies can assist providers to offset perceived self-concept deficits that could interfere with patients' HF self-care strategies.

As providers we must strive to go beyond simply telling our patients what actions to take to adhere to a HFDMP and expect them to be able to understand and follow. Instead we must make time to assess individual self-concepts or internal environment influences through HL assessments and cultural sensitivity. It could be that providers can reshape negative self concepts by acknowledging small achievements and recording noticeable signs of improvement as they occur. In our patient encounters, we can encourage patients to take note of how small steps are making their heart and body function or adapt better than usual to physical exertion and exercise. We can also encourage patients to draw support from their cohort by observing and supporting each others' experiences with self-care (Tierney, et al., 2011).

Three areas of measurement in the HF patient's experience brought forward by Barnason, et al. (2011) include – knowledge of HF, HF self-care, and self-efficacy. Measurement tools for each of the areas were either developed by primary investigators or previously constructed and validated such as the SCHFI. The study offers two ways by which self-care can be monitored. First, using pharmacy refill records, (indicating the patient takes their medication regimen seriously), and second journals to record and monitor trends in HF vital signs such as body weight, heart rate, blood pressure, and signs

of fluid overload by providers. Clinical HF studies rely on subjective self reports by patients as in the SCHFI. However, the literature states that patients do not consistently apply knowledge about their HF condition and HF self-care which may be partly due to inadequate HL levels and cultural barriers that are not addressed. It is conceivable that self-care deficits can be ameliorated with targeted interventions in a respectful way that can facilitate effective HF self-care agency.

In a qualitative literature review by Tierney, et al., (2011), four main themes emerge about how individuals respond to HF as a chronic illness. The themes of an altered body-sense, negative emotions, adjusting to an altered physical state, and interpersonal influences emerge as personal mitigating factors for individuals living with HF. Qualitative findings can give us intimate clues for developing strategies and interventions for HF care programs that will be meaningful for HF patients' self-care practices. Insights from patients' lived experiences with HF can further inform a SCDT-based framework for developing interventions that could bring greater success to behavioral changes, identify possible barriers, and support the outpatient HF population (Tierney, et al., 2011).

Heydari, et al., (2011), use a descriptive correlational design to uncover implications for clinical practice when dealing with HF patients. They concede findings similar to those put forward by Tierney et al. (2011) which is the notion that if providers understand HF patients' self-concepts (influenced by HL and cultural views) they can offer benefits of a HFDMP in a meaningful way that enables them to experience reduced symptoms and a better QOL. For instance, given HL limitations some patients may benefit from

frequent clinic follow-ups than others. This study gives a unique Iranian perspective on HF self-care that providers can draw from to add to their understanding of people from similar backgrounds within the HF population that they will encounter in some of B.C.'s HF outpatient clinics. The authors suggest that if HF patients perceive their HF self-care program as a threat to their self-concept they will be less likely to follow through with it than if they perceive it as a challenge and something they can adjust to. This valuable insight can help providers adjust their approach with HF patients of middle-eastern background and others who may express disappointments if they are not experiencing improvement in their symptoms and disease progression as expected. As a strategy, providers can talk some HF patients into viewing their condition as a challenge to their self-concept and something that they can learn to control, rather than viewing HF as a debilitating disease with little hope. The message to patients is they have a choice not to let HF continue to happen to them because step-by-step they can try to fit in daily self-care routines to monitor and maintain a stable HF experience towards a better or improved QOL.

A cross-sectional descriptive study by Britz and Dunn (2010), guided by the SCDT, on a small convenience sample ascribes a reduced QOL to untailored and indiscriminate knowledge-sharing which does not target individual HF patient's self-care needs. Self-care deficits such as poor medication management, poor diet control, and lack of exercise in HF patients can lead to poor QOL, increased hospital visits, increased morbidity, and increased mortality. The study illustrates the importance for providers to identify vulnerable HF patients who are at high risk for poor HF self-care based on their current

self-care deficits possibly due to underlying and underestimated HL and cultural sensitivity. Using the SCHFI as one of their data collection tools, investigators gather information about HF self-care deficits that are related to poor QOL outcomes. Insightful self-work needs to be done to enlighten and potentially motivate HF patients to develop their self-care ability or agency in controlling their own functional abilities despite their HF condition. Timmons & Horan in Britz & Dunn, (2010) recommend further studies to "demonstrate the importance of understanding self-care deficits of cardiac patients to improve the quality of care provided", (p. 481). This practice project adds that there needs to be attention given on the delivery or methodologies used to share evidence-based HF care, especially in an outpatient setting. When applied to an outpatient setting the SCDT positions providers to assist outpatients in gaining control of their HF condition by working with patients to develop skills that reduce deficits in knowledge, decision-making, and the ability to take action (Britz & Dunn, 2010). Previous studies reason that providers must assess individual HF patient characteristics that could affect the patient's ability to learn and process self-care behaviours before providing any interventions. The HF patient population in B.C. includes young and old, English and non-English-speaking, new comers to Canada, and old timers. For providers, the challenge towards self-care efficacy in outpatient HF care is making sure each individual understands and is motivated to safely monitor and medicate themselves. Investigators find that level of education and severity of symptoms impact self-care the most, (Britz & Dunn, 2010). Implications for providers from these findings are to consider patient's HL level and to intervene early when symptoms are becoming difficult to control. An earlier

study finds that female HF patients less than 65 years of age experience poor QOL compared with other age groups and men (Britz & Dunn, 2010). Further investigations can explain why QOL variances exist among this subgroup of HF patients, but for now providers can be alert to making time to accurately assess how female HF outpatients, overall, perceive their HF symptoms and self-care responsibilities.

The complexity of self-care deficits that can exist among a varied adult HF population brings into question the efficacy of delivering general, standard interventions, and guidance to HF outpatients. Tailoring educational interventions to individual needs can enhance self-care agency and HF outcomes. Individualized education can engender precise, sensible learning interventions especially after patients' self-care deficits have been accurately identified. Nurturing positive patient attitudes early in a HFDMP could influence their self-confidence to embark on a maintenance schedule of diet, medication, and exercise. Providers must heed the importance of developing patient-informed interventions in partnerships with HF patients. Self-care learning is subjected to a continuum of experiences in the outpatient HF journey and each patient-provider encounter is an opportunity to boost confidence levels. Future research to develop and test educational instructions that focus on building self-care confidence to improve HF patients' QOL at specific intervals of their HFDMP is needed (Britz & Dunn, 2010).

A Canadian HF clinic based at the University of Toronto uses the conventional model of a multidisciplinary team consisting of "physicians, nurse practitioners, a dietitian, a nurse, a psychologist, a pharmacist, exercise specialists, and social worker" (Seto, et al., 2011, p. 378). Despite the expertise available, surveys of patients using the

SCHFI and the MLHFQ (Minnesota Living with HF Questionnaire) show that patients remain under-served when it comes to knowing how to decide if and when they should self-adjust medication and HF self-care practices. The clinic sees a relatively younger HF population with an average age of 55 years in which there is no improvement in self-care or QOL measurements whether patients were enrolled early or late in the clinic at the time of the study. This suggests that patients do not necessarily benefit by simply enrolling in a HFDMP. This departure from expected improvements to self-care and QOL for patients attending a HF clinic deserves closer examination.

Four self-care barriers perceived by the participants in this study include: “1) lack of self-care education, 2) financial constraints, 3) no perceived benefit in self-monitoring, and 4) low self-efficacy” (Seto, et al., 2011, p. 380-381). Limited or confusing self-care information and anxiety over money constraints because of reduced earning power due to a heart condition can cause tensions when patients try to start basic self-care and find they have to purchase healthy food choices, and weight scales or blood pressure machines. Patients perceive no benefit from self-monitoring if they do not know how to interpret number readings to self-adjust their medication, salt or fluid intake. Low self-efficacy puts patients in a place of uncertainty and helplessness, particularly when they are not feeling well. There is a paucity of knowledge to explain specific self-care strategies for improving HF patients’ QOL despite personal situations, cultural backgrounds, and HL concerns. Patients identify a ‘blank’ period before their first clinic visit in which no one takes the time to explain next steps before embarking into a HFDMP. Having access to a HF health care provider in a pre-clinic period, (i.e. seven

days or less), can be an important first step to get patients on board with an outpatient HFDMP. Other authors point out a number of system failures in healthcare that does not adequately support HF self-care. These include poor use of clinical practice guidelines, lack of comprehensive record-keeping, poor communication between providers, lack of priority and accountability for providing self-care education services, and lack of provider insight into how to talk to patients about self-care (Seto, et al., 2011). Patients and providers can work together on developing HF self-care routines that are informed, adaptable, and aligned with achieving outcome benefits as suggested in the SCHFI.

Using the SCHFI outcomes of interest in HFDMPs can facilitate talking about HF self-care goals in a way that is consistent and easier for patients to understand, because the outcomes of interest are laid out in terms of what experiences the patient wants to have while living with HF. Providers can demonstrate a committed partnership incorporating teachable moments when reviewing patients' weights, blood pressures, and other concerns they have about their HF status. Providers can anticipate self-care strategies if they are aware of patients' individual health determinants that can be a barrier to self-care. Future studies are needed to confirm specific determinants of HF self-care through HFDMPs, but preliminary findings implicate certain patient related factors that providers need to routinely assess when considering patients' readiness or likelihood of engaging in self-care behaviours.

According to Seto et al., patients' with advanced HF and significantly reduced ejection fractions are either motivated to take better care of themselves or HF clinics do a better job of reinforcing HF self-care with this patient subgroup. Older patients are more

in tune with their bodies after living through HF symptoms for a longer time than younger patients, and they are less distracted and able to commit to self-care practices more consistently than younger patients. Other determinants that still require further investigations include: “younger age, male [and female] gender, higher education, better financial capacity, country patient is living in” (Seto, et al., 2011, p. 383) and number of co-morbidities or concomitant chronic illnesses. Assessing self-care characteristics can help providers work towards tailoring realistic and achievable HF self-care strategies that can fit into patients’ lives. Self-care programs can evolve as resources are optimized or become available to enhance a program in the direction that aligns even closer with achievable positive HF outcomes.

Health Literacy

“The main problem with communication is the assumption that it has occurred.”

– George Bernard Shaw

In the last decade, research has asserted heath literacy (HL) as a basis for “patients’ knowledge, health behaviours, health outcomes, and medical costs” (Baker, 2006, p. 878). However, it is not easy for experts to agree on a common construct for HL. The Institute of Medicine’s definition of HL is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Chen, et al., 2011, p. 447). In a broader sense and based on a literature review by Baker (2006), HL could be defined as a person’s capacity for reading, speaking, listening, numeracy and understanding of the health care environment that transforms over time due to aging and cognitive changes, health

conditions, differences in providers' expertise, educational programs, and systems of service delivery. Similar to the SCDT that suggests patients draw from internal and external resources to support their self-care, Baker (2006) describes an individual's HL as a function of internal and external environments, as well. Baker states "HL is determined by characteristics of both the individual and the health care system" (p. 880). The internal environments are physiological and psychological influences; while the external environments are the people and places that demand some degree of HL from the individual. Individual capacity for HL can fluctuate based on changes particular to their internal environment and changes to the external health care service environment.

Fluctuating levels of HF self-care can affect patients' abilities to interact consistently with providers and the health care environment. For people living with HF their disease condition can fluctuate depending on physiological changes coupled with every day stressors of living. Careful assessment of differences in patients' level of understanding and coping between visits needs to be monitored by providers, especially for cognitive weaknesses no matter the age of the patient (Chen et al., 2011; Heinrich, 2012). In some instances, HF patients may experience a drop in their literacy level the moment they arrive in the HF clinic or hospital setting - reasons for this are not ascertained but seasoned health care practitioners can intuit a combination of factors (Allingham, 2012), such as fear, language deficiency, and intimidation by the health care environment and health care providers. One factor that can dramatically affect patients' HL in a health care setting could stem from feeling judged by HF nurses and doctors when asked questions about their HF self-care progress. The nature of HF and the therapies used to

treat it does physiologically affect fluid levels, electrolyte and metabolic balances which in turn can alter the individual's capacity for HL or fully grasping what is being communicated by providers. Patients face fluctuating levels of physical and mental fatigue that can affect their ability to practice self-care adequately between outpatient clinic visits (Baker, 2006). This raises a primary issue of consistency in self-care agency by HF outpatients.

Baker (2006) makes a distinction between general literacy and HL. The former relies on "general reading fluency, vocabulary, and knowledge" (p. 879) or "the way that people use reading and writing in their daily lives" (Allingham, 2012, p. 42) - while the latter relies on "the person's health-related reading fluency, vocabulary, and knowledge" (Baker, 2006, p. 879). Baker reasons that this distinction between general and HL holds implications for future research which could be designed to investigate the association between general and/or HL as a predictor for health outcomes. Before attempting this, there will need to be a consensus reached among experts over what HL is, and how it can be appropriately measured. Dennison, McEntee, Samuel, Johnson, Rotman, Kielty & Russell (2011) agree that HL bears a complex construct that is not fully agreed upon by experts, and there is uncertainty if it can be accurately assessed. The authors assert that testing HL is challenging as respondents may find even the easiest questions difficult to understand and answer. Baker (2006) raises discussion about the necessity to measure HL and instead suggests the idea of "universal precautions" for HL. Baker's construct of universal precautions for HL involves "plain language, communication tools, and the teach-back method (having individuals repeat-back instructions to assess

comprehension)" (p.881). In the outpatient HF setting the utility of universal precautions for HL can enable easy-to-understand language skills either in person or in telecommunication methods, and this can become the expected standard of HF communication between patients and providers and between HF "hubs and spokes". This way all members of the HF team can speak the same language with patients and with other team members.

Dennison, et al., (2011) conducted a descriptive comparative American study using a small convenience sample in which the majority of participants are African American. The choice of convenience sample might reflect a societal bias that African-Americans will help capture evidence of low HL. Likewise, HF care providers in outpatient settings must recognize their own personal-held biases and assumptions about ethnic mix in the HF population and levels of HL. If providers could maintain a neutral stance in their interactions with HF outpatients this would mean giving HF patients a chance to safely expose their comfort level with HL, without fearing any judgment. Providers can avoid mistaking someone for being health literate when really they are not. Dennison, et al., (2011) agree with Baker (2006) that HL is a product of internal (individual) and external (social) factors. However, in contrast to Baker, Dennison, et al., encourage the use of HL screening tools such as the Short Form Test of Functional HL in adults (S-TOFHLA), and the Dutch HF knowledge scale along with the SCHFI. Chen, et al., (2011) agree the S-TOFHLA is "a reliable and valid measure of HL" (p. 448) with a Cronbach alpha rating of 0.98. The 36-item questionnaire is designed to be independently answered, as completely as possible within seven minutes. Score results categorize the respondent's

HL as being inadequate, marginal, or adequate (Chen, et al., 2011). In regards to the SCHFI, these authors accept an overall Cronbach alpha of 0.798 based on a longitudinal study that combined its maintenance and management subscales. In 2011, the SCHFI continues to hold appeal for investigators of HF self-care and the combination of the S-TOFHLA and the SCHFI offers stable methods for data collection for HL and HF self-care that can be used in future HFDMP research for outpatients.

Authors reviewed by both Baker (2006) and Dennison (2011), hold consensus on individuals with low HL as processing written material and information with difficulty. According to these authors, HF outpatients who are considered to have low HL are more likely to experience challenges in performing effective self-care than their counterparts with higher levels of HL. Poor self-care can lead to increased symptoms and poor outcomes in terms of reduced QOL, greater risk of hospitalization, and increased mortality (Baker, 2006; Chen et al., 2011; Dennison et al., 2011). In keeping with maintaining a supportive patient-provider partnership, providers need to accept patients as they are at whatever HL level they may be functioning at any point in time. Rather than subjecting HF patients to an environment of over-testing, providers can work on strengthening their own knowledge transfer and monitoring skills so that they can offset some HL issues experienced by patients.

HL tests can serve to identify the degree of HF knowledge and insight on the part of the patient, yet offer no solutions on how to deal with perceived deficiencies of the HL construct. Once tests establish that a patient has low or inadequate HL levels, there is no evidence-based algorithm that can support providers with how to proceed in knowledge

sharing or reinforcing self-care agency with this patient. Health care providers must be alert to different levels of HL that can exist in the HF patient population and be able to adjust their communication styles and approach when working in partnership with HF patients and their significant others in the outpatient setting. Developing standard screening for HL can be impractical and unreliable in a patient care setting, and can lead to added stress for vulnerable HF patients. Screening for HL in an outpatient HF setting can create an unpleasant experience at a time when patients need to feel accepted and supported, without judgement.

HL tests place the provider (and the system) in a position of power over the patient which engenders the traditional paternalistic dichotomy that patient-provider partnerships need to steer away from in today's health care environment, especially in an outpatient HF setting. Therefore the idea of universal HL precautions advanced by Baker (2006) is appealing and makes practical sense while offering a different notion on knowledge sharing for providers to apply when speaking to HF patients about their disease processes and treatment programs. Communicating in language that is easy for the HF outpatient to understand can make a HF self-care program less intimidating for patients to use. An interesting finding from data analysis by Dennison et al. (2011), is that HF "self-care management and maintenance did not follow expected patterns [of decline] across [low levels of] HL strata, and there was considerable within-strata score variance" (p. 363). This finding suggests that low HL levels can be augmented to achieve adequate levels of self-care out of need and necessity. Keeping in mind that HF patients' HL is a function of individual internal and external factors, a mismatch between external resource

availability and internal HL ability may create unmet self-care deficits which tend to lead to poor HF outcomes. Utilizing a HF self-care program based on simple language could help limit mismatches between internal and external factors when they occur and help patients stay on track with personal self-care.

Chen, et al. (2011) present a cross-sectional study that recruited a convenience sample of forty-nine HF patients from a variety of community settings in the American state of Indiana. More than half of the sample were white males with a mean age of 72 years who had a high-school or greater education background. Examination of the notion that HL is a necessary prerequisite for HF patients to successfully navigate health care systems and practice self-care shows that patients with adequate HL do demonstrate better self-maintenance (behaviours that promote stability), while those with inadequate HL demonstrate better self-management (behaviours that respond to symptom exacerbation), (Chen, et al., 2011). On the other hand the finding of inadequate HL patients performing better self-management means that these patients are inadequate in maintaining stability of their HF condition through routine self-care. However, for some patients it could be that it is not until they experience severe symptoms that they are motivated to find ways to manage their HF exacerbation.

Health literate patients who maintain routine self-maintenance and therefore achieve a level of HF stability are less likely to experience symptom exacerbations that they need to manage. Meanwhile, inadequate HL patients are capable but less motivated or disciplined in self-care maintenance. This suggests that self-care requires not only motivation but a degree of self-discipline that needs to develop over time. HF patients

have to learn what HF is, what signs and symptoms to watch for, such as ankle swelling, weight gain, and shortness of breath, and how to cope with these. To perform self-care well HF patients require a functional level of HL and they have to be able to articulate perceived changes and barriers to optimizing their self-care agency. Self-care activities that require HL skills include interpreting prescription labels, blood pressure readings, weight changes, food menus and knowing if any adjustment to maintenance is needed in order to avoid major symptoms (Chen, et al, 2011). Intuitively, low HL can limit self-confidence in performing self-care and might result in a lack of commitment to follow through with monitoring and intervening when HF signs and symptoms call for action. However, in their data analysis Chen, et al. (2011) found that the relationship between HL and self-confidence though positive was not statistically significant although this may be due to a small sample size of forty-nine and variable lengths of time that patients in the study were living with a HF diagnosis. Those who have HF longer might have opportunity to develop their self-care confidence and skills over time. The investigators contend that the naturalistic cross-sectional design of this study provides a snap shot of a current state in HF outpatient settings, and that "longitudinal studies are needed to examine the relationship between HL and self-care over time to understand how HL interacts within the self-care process in HF" (p. 450).

Another American study attempts to prove a direct relationship between general literacy and HF QOL; while considering if HF knowledge, self-efficacy, and self-care behaviours can influence this relationship. The study does not define its construct of general literacy and makes no mention of internal and external mediating factors for the

patient; nor does it discriminate between general literacy and HL. The reader therefore might assume that the study is hypothesizing a relationship between general literacy and HF QOL and this can imply a different concern for providers who interact with HF patients. An assumption that patients are capable of general literacy means providers need only focus on enhancing health related literacy. If patients are lacking general literacy, this implies a weaker foundation for adding on health-related literacy. The study uses the S-TOFHLA on a cross-sectional sample of 585 HF patients from mixed ethnicities, but in which African-Americans were the second largest group. The study bears some resemblance to the study done by Dennison et al. Investigators identified barriers to positive HF outcomes that could be applicable in a Canadian context too, namely: communication difficulties, lack of self-maintenance support, poverty, and poor access to appropriate care (Macabasco-O'Connell, et al., 2011). The authors note that a number of studies between 1997 – 2002 report an association between low HL and "poor knowledge about health conditions, less use of preventive services, higher hospitalization rates, increased mortality, and poorer self-reported health status" (Macabasco-O'Connell, et al., 2011, p. 979).

Macabasco-O'Connell, et al., (2011) support previous findings that reduced HF QOL is not always a function of low literacy alone. Patients with low literacy may be exposed to more HF education as a result of clinic visits, hospitalizations, and closer monitoring by providers which helps mitigate the gap between baseline low literacy and achieving adequate HF knowledge, self-care, self-efficacy and an improved QOL. This finding does not support the hypothetical model where low HL leads to reduce HF QOL

experiences. However, the findings could support an alternate model in which patients with low HL may be coached by providers to transcend perceived gaps in their HF knowledge, self-care efficacy, and self-care behaviours to realize an improved HF QOL.

In a literature review to develop methods for teaching HL to health providers, Coleman (2011) asserts that providers lack skills in utilizing HL principles as outlined in The Calgary Charter on Health Literacy (2008). Coleman is one of the authors on a panel that constructed a charter outlining the core principles for HL. The charter was constructed after three days of discussions between health care and literacy representatives from Canada, the United States, and the United Kingdom. The core principles for HL curricula development are summarized in Appendix C.

HL principles are important to every clinical encounter between patient, provider, and system. However, developers, researchers, and evaluators have much work to do in building an evidence base for HL that explores connections between “individuals, communities, systems, cultures and health outcomes” and “how HL interventions work” (Coleman, Kurtz-Rossi, McKinney, Pleasant, Rootman, & Shohet, 2008, p. 3). Meanwhile, providers must learn to facilitate patient encounters by refraining from using medical jargon and sharing information in ways that are easy for the patient to understand and act on. A ‘teach back’ intervention where the patient is asked to tell the provider the instructions received, in their own words helps to assess patient understandings in the moment (Coleman, et al., 2008). A well known strategy of “Ask Me 3” developed for a pediatric population can be applied to adult HF patients for organizing health information from a patient’s perspective, the questions in this framework are:

1) What is my main problem?

2) What do I need to do?

3) Why is it important for me to do this?

(Evangelista, et al., 2010, p. 14).

The Institute of Medicine recommends that professional schools incorporate HL in their curricula especially in nursing where there seems to be 'striking absence' of such training. Conceptually, HL education can enhance professional skills and attitudes that can impact behavioral changes in patients towards improved health care outcomes. As providers gain confidence in their HL skills, they can engage in anticipatory guidance in patient partnerships to address health care conditions and self-care practices more specifically (Coleman, 2011).

Given the small amount of investigative work done in HL, a short summary of implications for clinical practice and future research are worth mentioning. Between 2006 and 2007, three interventional studies for HF patients revealed that limited HL puts patients at risk, compromises patient-provider communication, and negatively impacts quality of self-care skills that are essential in HF maintenance and management. Inadequate HL is associated with poor HF outcomes, worse physical and mental health, higher mortality risk, and a tendency towards increased comorbidities (Evangelista, et al., 2010).

Investigators give a detailed description of how a health literate individual behaves. In their view, a health-literate individual has the ability to comprehend complex vocabulary, share personal information with providers, make healthy lifestyle decisions,

perform self-care, and navigate a complex health care system (Evangelista, et al., 2010). This sounds like an idealistic description of a healthcare-seeking individual untouched by human imperfections that are known to exist. However, the investigators go on to suggest people who have general literacy skills in normal situations and in familiar environments can demonstrate inadequate HL when faced with a stressful health-related situation in a confusing health care environment where communication occurs using medical and health-related terms. Patients and their families or support persons can find themselves in unpleasant, vulnerable positions when circumstances require seeking help and guidance from those perceived as being highly knowledgeable and learned in health matters.

Patients can feel intimidated by providers and the health care environment. Patients with reading problems may feel embarrassed or ashamed as they try to hide their inability to read from family members and health care providers. Evidence suggests that providers should not minimize patients' HL problems but rather be sensitive to the impact low HL can have on patients' illness experience, self-confidence, and health outcomes. For the outpatient HF population timely acknowledgement of low HL and tailored interventions need to be a priority in early clinic visits to facilitate reaching desired HF outcomes in the coming months.

Providers can however feel ill-equipped to support patients with perceived low HL which might even be a sign of cognitive impairment due to severity of HF and reduced cerebral blood flow (Evangelista, et al., 2010). Providers have to approach HL whether real or acquired as a potential barrier to the evidence-informed care and service they are

trained to provide for their patients. Evangelista, et al., (2010) advance a dedicated, unbiased multidisciplinary approach by core practice leaders as one strategy to bring focus to HL in inpatient and outpatient settings. Providers need to respect HL limitations as an opportunity to positively impact health outcomes during patient assessments. Patients and their families need reassurance that HL limitations are normal in their illness experience and can be methodically addressed to reduce ongoing tensions of inadequacy and embarrassment. Providers have to involve patients in their care and treatment choices and guide them in learning about their illness and addressing feelings about having the illness. Positive health outcomes are achievable when patients feel supported in adjusting and improving self-care. It is important for providers to evaluate patients' learning styles including language, verbal, written, or hands-on preferences for knowledge transfer.

Assessing HL in HF patients is crucial to the success of HF self-care programs that require patient involvement. Adequate HL is necessary for interpreting treatment information, following treatment plans, communicating with providers and navigating the health care system (Robinson, Moser, Pelter, Nesbitt, Paul, & Dracup, 2011). Earlier studies link low HL to "older age, limited education, lower income, chronic disease, having English as a second language and poor mental health status" (p.887). A relationship between HL and cognitive function especially in the elderly has yet to be fully explored. Evangelista, et al. (2010) provides a five-step process for providers to address low literacy assessments of their patients, along with a list of possible signs of

low HL for providers to recognize, and tips for effective communication strategies. These tools can be found in Appendix D.

Intuitively, as providers we might suspect that older persons with HF could experience shifts in their HL abilities because of cognitive changes and what they are experiencing in their HF condition. Robinson et al. (2011) raise awareness that intuitions can be misguided. Performing accurate HL assessments in the older population can identify those who can follow self-care programs if given a slower pace, and short frequent reinforcements. Within the HF patient population there will exist those who instantly grasp self-care principles and those who may take longer to understand but still are capable of participating in HF self-care. There will also be some people who require caregiver help and more structured health education specific to their self-care abilities.

Providers face a challenge to identify and implement specific educational interventions for their HF patients as many will have some form of cognitive impairment interfering with their “capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Robinson, et al., p. 887). Providers may fall into the traps of over and under estimating patients’ HL abilities, and, either way not be able to provide adequate educational interventions. Conversely, patients may find themselves under- or over-informed in how to perform self-care activities that can impact their symptoms and HF condition. Ongoing HL assessments are necessary in outpatient clinic settings to detect fluctuations in HL levels especially for those predisposed to cognitive dysfunction such as the elderly, under-educated, low income, and mental health deficit groups.

Robinson, et al. (2011) make a good point about the widely-used seven minute S-TOFHLA tool for measuring HL which they suggest poses a disservice to HF patients, their providers, and their surrounding support network. The S-TOFHLA challenges already vulnerable HF patients to respond to as many questions as they are able in seven minutes and the score results separate respondents into inadequate, marginal, and adequate HL categories. Robinson, et al. (2011) examine the "relationship between the S-TOFHLA literacy levels between the standard seven minute times test and with no time limit (NTL)…in a group of community dwelling" (p.888) HF patients. This study belongs to an ongoing Rural Education to Improve Outcomes in HF randomized clinical trial. The trial examines "an education and counseling intervention to improve self-care" (p. 888) in HF patients. The patient demographic for this study was carefully selected to avoid confounding variables that could potentially influence respondents' performance on the seven minute or NTL S-TOFHLA. Six hundred and nine patients undergo a mini-mental status screening and only those meeting selection criteria are in the study. The selection criteria included: age 18 years and above with stable HF; hospitalized for HF in the last 12 months; "able to read and write in English and living independently with primary decision-making ability" (Robinson, et al., 2011, p. 888). "Patients were excluded if they had a complicating serious comorbidity,... a psychiatric illness or untreated malignancy, a neurologic disorder that impaired cognition, or concurrent participation in a HFDMP" (p. 888). A previous case-controlled study that already links HF and cognitive impairment such as "orientation, attention, memory, executive function,

motor speed, and reaction times" (p.890), finds HF patients are more than four times likely to have cognitive impairment than control subjects (Robinson, et al., 2011).

Robinson et al., (2011) find no strong direct correlation between HL and HF knowledge, reports of self-care behaviours, and emotional distress between the seven minute and NTL tests. The authors admit self-reported data in the S-TOFHLA is one study limitation as well as imposing a test on patients who may have subtle cognitive impairment not detectable by screening tools. The authors attribute findings to long term HF care guided by cardiologists, and different techniques for measuring knowledge, self-care and emotional stability. Robinson, et al., (2011) suggest that low literacy scores can mask cognitive slowing related to age, disease progression, and other organic causes. Patients' abilities to process information can be disrupted by their internal environment. The STOFHLA does not make allowances for responders who are non-English speaking or who use English as a second language. The test also does not take into account patients who may have some physical disability that prevents them from moving quickly through the test. S-TOFHLA participants were insistent that they be allowed to complete the test past the seven minute mark and then be adjudicated into a HL level, as they were confident they could successfully complete the test, and likely qualify for a higher HL level, if given more time.

Providers must skillfully conduct accurate assessments of patients' HL abilities. Providers must prepare to give HF patients variable amounts of time to absorb information, in order to refrain from unfairly burdening patients' families or significant others with added HF education. Lifting time constraints when speaking with patients

about their HF and self-care program in a quiet, supportive, unrushed outpatient setting would be helpful. The pay off for providers could mean having patients more on track with their HF self-care programs and longer trends of earlier, more positive HF outcomes. Providers who work together in HFDMPs need to develop a consensus on how in depth, and how frequent HF education and communication has to be with specific HF patient subgroups in their demographic area. When HF patients arrive in outpatient HF settings the task at hand is to work with patients at the HL level they are at and to get on with the work of HF and self-care education. Over-testing patients can be misleading especially in a population that is prone to cognitive changes. It would be more pragmatic to have periodic check-ins using less time-consuming but reliable tools such as the S-TOFHLA with NTL that patients can complete in a supportive, non-judgmental clinic environment.

HL tools seem to be designed for use in healthy adults without cognitive or physical impairment. This is a challenge when applying HL tests to HF patients who likely have some degree of cognitive decline that remains undetected. It may not be practical for providers to test for HL levels in an outpatient HF setting. However, providers need a framework to recognize patients with low literacy and be able to intervene appropriately. Tools refined in rating patients' HL in feasible timeframes and manners are necessary. Organizing HL screenings within an acceptable time frame in an outpatient HF setting is an important consideration for providers. For now using the S-TOFHLA with no time limit is one option – although this design still runs the risk of inaccurate HL assessments. Robinson et al. provide findings from a meta-analysis that suggests regular (but not over-

frequent) re-testing in combination with remote monitoring of HF care is one way to maintain surveillance on functional HL levels. Busy outpatient settings could provide frequent, short education interventions inclusive of family and significant others who can help reinforce HF teachings in a non-threatening way, as needed. It is important to recognize the extra time and effort asked of family members as they support the HF patient at home. Acknowledging the tensions of responsibility, fear, guilt, anger, and disappointment that they can feel and supporting them through the emotional ups and downs they will feel as caregivers should also be integrated into outpatient HF management strategies. This topic is beyond the scope of this project paper; but for now, repetition of HF education and ongoing assessments remain critical to ensure patients have access to strategies that can enhance their HF self-care knowledge.

In a two part comparison study published in 2007, the performance of the Newest Vital Sign (NVS) was compared against the Rapid Estimate of Adult Literacy in Medicine (REALM) and the S-TOFHLA. REALM is an 8-item word recognition test designed for a rapid literacy assessment in a busy clinical environment. Both the REALM and the S-TOFHLA are modeled on general literacy measures but are designed to give HL estimates (Osborn, et al., 2007). In theory, the Institute of Medicine (IOM) sup-ports the assessment of HL as the sixth vital sign, and recommends HL assessment as part of quality data collection on patients (Heinrich, 2012). Some may argue that routine HL screening subjects patients to embarrassment, anxiety, and alienation; while others reason that patients may be relieved that there is consideration given to helping them understand health information and what to do with it. In contrast to the 22 minute

TOFHLA against which it was validated a 3 minute HL screening tool called the Newest Vital Sign (NVS) exists in English and Spanish and is developed for use in outpatient settings. The NVS tool is available on the Pfizer Clear Health Communication Initiative website (http://www.pfizerhealthliteracy.com/physicians-providers/Newest VitalSign.aspx). It uses an ice-cream label to test individual understanding and application of words, numbers, and forms by asking six questions. Its design makes it feasible to use in a busy outpatient care setting as another option for outpatient HF Clinics.

The NVS was examined for detecting literacy levels and predicting health outcomes. Participant interviews collected socioeconomic and demographic data and completion of self-report health assessment questionnaires consisting of true or false questions, a 13-item knowledge assessment, and a 4-item medication-adherence recall collected other data. The NVS came through as demonstrating a stronger correlation with the S-TOFHLA in terms of detecting limited literacy, but it is less effective for predicting health outcomes. A major limitation of this type of comparison study is the potential for "test fatigue" among participants who are subjected to a preliminary data collection interview prior to filling out the actual test tools. This type of study design can confound test scores as participants may develop internal learning, confusion, or apathy for how they respond to questions. The study supports the notion of determining HL deficits as long as there is some recourse. Health care providers can use literacy screening tools only if they are ready and willing to use appropriate communication strategies for patients with limited literacy. HL screening requires some sort of follow-up and can

place the responsibility of dealing with HL deficits onto providers and health care systems.

On another note, Heinrich (2012) suggests that HL screening scores need to be circulated to "other specialist healthcare providers, pharmacists and acute care settings" (p.222) so that provider-patient communication can be adjusted and kept uniform for patients' health care experiences. Sharing HL scores between different provider settings is an idea that needs thoughtful consideration. Providers have to remember that HL is a dynamic, complex phenomenon that can fluctuate because of changes in an individual's health status or experience and their ability to make sense of information. Effective communication strategies as outlined in Appendix E can facilitate sharing information between providers and patients.

Heinrich (2012) views HL as a dynamic concept subjected to being influenced by the type of health problem the patient is experiencing, the provider's knowledge and ability to help, and the positive or negative nature of the information shared. Heinrich speaks of culture and society, the health care system, and education system as having direct impact on HL. The "ideas, meanings, and values" held by individuals because of the societies they belong to can inform the individual's cultural identity, their worldview, and how they learn in it. Other factors that can influence an individual's HL are "native language, race, ethnicity, socioeconomic status, gender, communication style, gestures, and word definitions" (p. 219) which can differ between cultures. The need for cultural sensitivity in supporting HL segues into this project's next section on enhancing outpatient HF self-care through cultural sensitivity.

Cultural Sensitivity

"Demography is destiny, demographic change is reality, and demographic sensitivity is…imperative" (Giger et al. 2007, p. 96)

Over the last decade cultural sensitivity has been viewed as a trendy word in health care, and it can have multiple interpretations; the term is sometimes used interchangeably in the literature with cultural competence. An observation is that a distinction between the two terms seemingly emerges out of the literature that favors viewing cultural sensitivity as an awareness characteristic whereas cultural competence is the skillful enactment of this awareness. Foronda's (2008) concept analysis of cultural sensitivity is informed by literature searches in disciplines outside of nursing giving rise to a comprehensive interpretation of what cultural sensitivity means. The definition put forward by Foronda (2008) is: "Cultural sensitivity is employing one's knowledge, consideration, understanding, respect, and tailoring after realizing awareness of self and others and encountering a diverse group or individual" (p. 210). The author goes on to say that cultural sensitivity "results in effective communications, effective interventions, and satisfaction [through diverse encounters]" (p. 210) or cultural competence. In support of cultural sensitivity, cultural diversity is not limited to only race and ethnic background. Diversity can include religious affiliations, language, disabilities, sexual orientation, gender identification, socioeconomic status, geographic location, and access to technology to name some attributes (Campinha-Bacote, 2011; Schim, Doorenbos, & Borse, 2005). For the basis of this paper, focus will be given to the traditional ethnic sense of diversity, which tends to be apparent in HF outpatient populations. The reader is asked to apply insights regarding ethnic diversity to other situations of diversity that

can also exist within any patient population. Characteristics of diversity can exist between provider and patient who share the same ethnic heritage. However, assumptions of cultural understanding cannot be made based on the appearance of cultural concordance between patient and provider. Intracultural variations add another complexity and emphasis for ongoing processing of cultural awareness, skill, knowledge, patient encounters, and desire to do so on the part of the provider (Campinha-Bacote, 2011; Morton, 2012). Schim, et al., 2005 add that “recognition of personal attitudes, values, beliefs, and practices with one’s own culture and insight into the effect of self on others” (p. 356) is a necessary characteristic of cultural sensitivity. Health care disparities among patients of diverse backgrounds can be viewed not only as a function of providers’ low cultural competence, but also as a result of a lack of provider awareness of their own personal biases and health organizational beliefs and attitudes regarding patient populations from different cultural backgrounds. Health care systems and providers need to become more mindful of unmet needs for vulnerable patients who seek guidance, and care in a health care setting (Horner, et al., 2004; Ingram, 2011; Sumpter & Carthon, 2011).

Over the years immigration and births have lead to a proliferation of people from different ethnic and socio-economic backgrounds within Canadian communities. Rapid travel and evolving technology have brought about demographic shifts and cultural diversity in Canada and the U.S., as well as other countries like Australia and the United Kingdom (Schim, et al., 2005). Globally, health care providers are pressured into responding with appropriate manners to diverse patient populations that have different

communication styles, multiple languages, attitudes, expectations, and viewpoints. Literature informs us that “racial and ethnic minorities are burdened with higher rates of disease, disability, and death, and tend to receive a lower quality of health care than non-minorities” (Anderson, et al., 2003, p. 68). In most countries, an emerging socio-economic trend of low income earners is noticeable among people of racial or ethnic minority and as a result “the health status of immigrant, refugee, and ethnic minority populations is often worse than that of the average population” (Horvat, Horey, Romios & Kis-Rigo, 2011, p. 3).

In British Columbia we have multicultural, ethnically diverse patient populations living with HF that have universal health care available to them. Yet shortfalls within our health care system persist, and fail to universally address the unique needs of our diverse population through policies, procedures, and practices. Some people perceive culture as a health care barrier to realizing their optimal health outcomes, especially if their background is quite different to that of their health care providers (Majumdar, Browne, Roberts, & Carpio, 2004). A commentary in the early part of this decade from the Canadian Medical Association Journal warns that race is a social rather than a biological construct whereby providers develop an unconscious bias and resort to ineffective communication and behavior patterns that can impair health service delivery and health outcomes for select patients. Clinical literature asserts that negative attitudes can consciously or unconsciously shape providers’ behaviours and influence their clinical decisions in a negative way during patient encounters (Anderson, et al, 2003). As patient populations become increasingly diverse, “cultural competence [through cultural

sensitivity] and freedom from bias are becoming increasingly urgent professional responsibilities" (Geiger, 2001, p. 1700).

In order for patient-provider partnerships to be effective in outpatient HF care it helps if providers can speak the patient's language or are sensitive to cultural differences inherent in patients' experiences. Measures can be taken to reduce or eliminate compromises to health care service delivery and outcomes. Health care environments such as HF outpatient settings are generally busy places where providers experience 'time pressures' and the need to multitask which can stimulate stereotyping patients resulting in "application errors" that can be prohibitive to meaningful communication. Providers can shape outpatient HF patients' experiences and their willingness to apply HF related information to their HF condition through consistent cultural awareness and communication that is sensitive to patients' unique situations. If providers are willing to explore the basis of personal cultural biases, and become more open-minded to learning about cultural underpinnings of patients' thinking and behaviours in regards to HF self-care, it would be easier to engage in meaningful dialogue for sustainable strategies to support HF self-maintenance (Anderson et. al., 2003; Ingram, 2011).

Cultural sensitivity requires ongoing practice and self-evaluation on the part of the provider and it can influence providers' behaviours to become more understanding of patients' needs and expectations. Different authors support the notion of nurses journeying into becoming culturally competent through self-reflecting and developing awareness of personal cultural values and beliefs and identifying potential conflicts between their own cultural values and others' which could lead to barriers in developing

therapeutic partnerships (Campinha-Bacote, 2011; Douglas, et al., 2011; Foronda, 2008; Horner, et al., 2004; Ingram, 2011; Majumdar, et al., 2004; Morton, 2012). Patients' experiences in a health care system that is in tune to their individual needs can engender a stronger ownership of HF self-care programs through which improved long-term HF outcomes can occur (Campinha-Bacote, 2011; Foronda, 2008; Ingram, 2011; Majumdar, et al., 2004; Morton, 2012). Culturally sensitive care is known to be associated with good patient-provider communication, improved engagement with health – illness practices, less burden on health care systems, and positive patient outcomes (Schim, et al., 2005). It is therefore important for providers to approach encounters with patients from diverse cultures with an attitude of humility, respect, and a willingness to negotiate strategies in health promotion, disease prevention, health restoration, and palliation (Schim, et al., 2005).

In the 1970's a nurse-anthropologist named Madeleine Leininger introduced the Trans-cultural Nursing Theory which blended nursing and anthropology concepts to produce culturally congruent nursing care. In later years, Campinha-Bacote blended transcultural nursing with transcultural medicine to create a "culturally conscious practice model of healthcare delivery" (Campinha-Bacote, 2011, p. 42). Since 1991, the Process of Cultural Competence (PCC) has evolved and draws on Leninger's previous work along with others to comprehensively outline cultural competence as "the ongoing process in which the healthcare professional (HCP) continuously strives to…work effectively within the cultural context of the patient" (Campinha-Bacote, 2011, p. 42).

The PCC is designed for providers to become rather than be culturally sensitive to the needs of their patients and it is underpinned by five integrated constructs "cultural desire, cultural awareness, cultural knowledge, cultural skill, and cultural encounters" (p. 42). Providers can use the PCC as a guide for how to engage in all encounters with individuals they come into contact with on a daily basis. PCC is not meant to be restricted only to the providers' professional life, but can also expand and apply to providers' engagement with all others in a more mindful manner regardless of cultural background. Among the five constructs of PCC, cultural encounters have been identified as pivotal to the process of becoming culturally competent. Cultural encounters provide the backdrop for the PCC to be applied in mindful interactions through all forms of communications (face-to-face, telephonic, and electronic). Different encounters help providers to "validate, refine, or modify existing values, beliefs, and practices about cultural groups" (Campinha-Bacote, 2011, p. 43) and continually evolve one's thinking.

In outpatient HF settings in B.C., providers are positioned to be able to augment HF outcomes by connecting with culturally different patients on a level that could move this patient population to commit to a prescribed method of HF self-care maintenance. Cultural encounters enable providers to directly and specifically ask questions about patients' backgrounds. Through these encounters, providers can develop and practice culturally sensitive interview skills in order to garner relevant information from patients about their HF experiences and become more intuitive to performing culturally sensitive physical assessments. Through repeated encounters, providers become more skilled in culturally sensitive styles of inquiry to obtain meaningful information that will help

diagnose the patient's problem and decide a mutually acceptable treatment plan (Campinha-Bacote, 2011; Morton, 2012). Campinha-Bacote (2011) suggests that if providers practice from a culturally sensitive perspective in all patient-provider encounters, without being judgemental, they can then make connections where patients will feel valued, respected, and supported. See Appendix F for the PCC model's self-examination questions for providers represented by the mnemonic ASKED which stands for awareness, skill, knowledge, encounter, and desire.

At an American symposium on musculoskeletal health care disparities, a hypothesis put forward is that insensitivity and inattention by health care providers to cultural contexts of patients' experiences can contribute to inequities in health care for ethnic groups (Dykes & White, 2011). There is a paucity of evidence to support this notion of conscious or unconscious caregiver bias and limited cultural competence as contributors to disparate health care. This notion poses a challenge to any assumption of unbiased caring on the part of health care givers. It draws attention to the need for "evidence based educational strategies that [can] produce changes in caregiver attitudes and behaviours and, ultimately, reduction in healthcare disparities" (Dykes & White, 2011, p. 1813), when required. Providers can demonstrate cultural competence in their manner of being and interacting with patients from diverse backgrounds and belief systems that influence their health and illness perceptions and responses to diseases, symptoms, and treatments. In their encounters and partnerships with patients, providers need to develop skills in recognizing and responding unconditionally to age, gender, social demography, and cultural biases in health care delivery and focus on achievable health outcomes for

patients. Cultural competency skills, like clinical skills have to be developed and utilized by providers when interacting with patients in order to reduce health care disparities among our patient populations (Dykes & White, 2011).

In 2004 a mixed method Canadian study done in Ontario examined the effect of cultural sensitivity training on patients' health outcomes in a randomized control trial over an eighteen month period. In an earlier study done in 1999, one of the study's investigators (Majumdar) found that cultural sensitivity training helped providers to become more open, resilient, self-confident, non judgmental, able to deal with ambiguity, and able to better understand others. The 2004 study showed that culturally sensitive interventions such as improved patient-provider communication can help reduce disparities in health care services resulting in improved patient health outcomes.

Health care disparities in delivery and outcomes have become a source of major inquiry in countries with growing racial and ethnic populations. Research shows that despite equal access to health care, there are differences in the use of diagnostic tests, information, and treatment options provided to members of diverse ethnic backgrounds (Horner, et al., 2004). Expert panels of professionals from nationally recognized organizations have examined this controversial topic to try and identify interventions that could change cultural competence behaviours of health care providers. Cultural competence training, certification, and ongoing evaluation plus modification of health services to be culturally acceptable are high level provider-focused interventions that health care systems need to invest in. There is a paucity of evidence around effective mechanisms to assist providers in achieving cultural competence (Horner, et al., 2004).

However, repeatedly it seems the process of becoming more culturally competent begins with an awareness or self-assessment of one's own culture and understanding of culture and its relationship with health and health care. Sensitivity to another's culture requires developing skills to address health related issues in a manner congruent with that individual's culture. Ongoing evaluation of techniques and outcomes measurements for chronic conditions such as HF and effectiveness of patient-provider satisfaction with communication processes during clinic visits can reflect trends in the ways patients are being successfully managed (Horner, et al., 2004).

Langer (2008) suggests that in order for patient-provider partnerships to flourish communication which is clear, timely, and culturally sensitive is a necessary ingredient, especially when working with an elderly patient population. Langer presents issues in patient-provider communication patterns that can engender poor participation by patients in a HFDMP resulting in fractured outcomes for all stakeholders – patient and family, providers, and the health care system. Patients' willingness to follow advice from their health providers can fall into a spectrum of participation that ranges between dropouts, non-participants, participants, over-participants, and abusers. The problem with health maintenance or management behaviours on either side of therapeutic participation is that HF goals are not achieved as anticipated and could lead to unexpected problems. Patients tend to hold onto preconceived notions and beliefs regarding their susceptibility to HF, its severity and influence in their daily living (Langer, 2008). Perceived complexities of self-care requirements, HF therapies, and side effects, can influence the willingness of a HF patient to adopt HF self-care behaviours.

The quality of patient-provider partnership can help mitigate self-care issues for patients. On the one hand, providers value participatory partnerships as a component of HF outpatient self-care to achieve health outcomes that “outweigh the impact of social, psychological, and economic factors on the patient’s life” (Langer, 2008, p. 387). While on the other hand, “patients value convenience, money, cultural beliefs, habits, [and] body image” (p. 387). “Patients [tend to] use their judgement when presented with a medical protocol and decide if to adhere to the protocol and/or which components of the protocol they will adhere to from their subjective, cultural, autonomous life view” (p. 387). Providers must be sensitive to patients’ views and resist slipping back into the ‘health expert, paternalistic’ dichotomy when interacting with patients. It is important to acknowledge and validate patients’ self-determinism in finding ways to come to terms with how they will cope with their HF condition and self-care agency in the context of their individual lives. Despite evidence that shows HF self-care protocols are of proven value, the individual patient may perceive any attached “emotional, psychological, social, physical, and financial” (p. 387) concerns are ‘too much to take’ for some undetermined benefit. Langer suggests that it seems more realistic to view patient-provider partnerships as a place where the responsibility of HF outcomes is jointly shared. Poor patient participation occurs due to a poor communication pattern between provider and patient, instead of being a maladaptive characteristic of the patient. This standpoint could support a framework for patient-provider partnerships in outpatient HF settings and will need grounded research to evaluate methods or patterns of communication between patient and provider that lead to HFDMP participation and positive HF outcomes.

According to the framework put forward by Langer, providers in an outpatient HF setting can create a backdrop that will make it easier for patients to want to choose to sustain their individual HF self-care program. Patients can experience confusion, uncertainty, and a lack of clarity about how to optimize self-care after leaving clinical settings. Providers can exercise careful and empathetic [HL-appropriate, and culturally sensitive] communication. If HF patients experience supportive communication in their patient-provider partnership, there lies a good chance they will follow through in their self-care strategies. Good listening in a patient-provider partnership involves nonverbal communication and Sepkowitz in Langer 2008 offers this advice to providers: “maintain composure and neutral facial expressions”.

By being present during patient encounters, providers can make patients feel worthwhile and accepted. Providers can help patients feel comfortable to explore options that could optimize their abilities to participate in a HFDMP successfully. In contrast to therapeutic communication patterns with patients, providers need to avoid “unhelpful communication behaviours” or patterns such as: “interrupting patient’s explanations, preaching, blaming, extensive[ly] probing, and questioning – especially with probing ‘why’ questions, and adapting a patronizing attitude” (Langer, 2008, p. 389). Langer asserts that unhelpful communication patterns can encourage avoidance, and important health issues remain unexplored. Vulnerable HF patients need time to reflect on what their illness experience has been in order to be able to give accurate reports of their disease progression and QOL impact. Patients should be encouraged to keep a journal that they can bring with them to their clinic appointments, keeping a list of current meds,

and instructions from the last visit can also facilitate communication between patient and provider. Empathetic communication between patient and provider ought to be based on: respect, trust, being concise, jargon-free, and concrete. Patient and provider ought to feel comfortable in seeking clarification and checking perceptions.

As providers we must not forget that patients are in charge of their lives and are free to make choices despite perceived restrictions because of their environmental, biological, and personality constraints. Providers' understanding of patients' context can be enhanced by developing sensitivity to how patients' behaviours are influenced by their socio-cultural backgrounds. Providers need to assess patients' HL levels before sharing knowledge information. Storytelling opens up opportunities to assess "cultural orientation, health belief system, and psychological orientation towards the condition" (Langer, 2008, p. 391). Taking time to listen to patients' narratives can validate their sense of self-worth and ability to engage in self-care programs. Providers can use narratives to humanize rather than 'medicalize' communication patterns with patients around components of HF self-care in order to engender a cooperative patient-provider partnership (Langer, 2008).

Langer goes on to point out the uniqueness of "minority elders" who can make up a large portion of the outpatient HF patient population. According to the author, this group of patients come from a history of discrimination and segregation where access to "status, resources, and opportunities were determined exclusively by race, ethnicity, and gender" (Langer, 2008, p. 392). Poor or culturally insensitive approaches with this group of individuals run the risk of increasing patients' dissatisfaction and maladaptive

tendencies. Langer suggests that past experiences and cultural beliefs, values, and attitudes can strongly influence how elderly HF patients could perceive their condition and treatment plans. A HF patient's beliefs can influence the way they perceive symptoms and how they decide what is important and when it is time to intervene or seek provider support. If providers are not sensitive to patient's personal beliefs around their HF self-care this could lead to missed opportunities to engage with patients at a level that would ensure better use of HF self-care knowledge which could lead to improved outcomes sooner. Langer provides sets of cultural assessment questions that providers can use, one helps the provider to "understand the world view and social organization of the patient"; while the other can be used to "elicit medical information that is...socially and culturally less stressful to the patient than a customary medical interview" (p. 393). Both assessment sets are listed in Appendix G.

Sumpter & Carthon (2011) provide an assessment of nursing students' perception of cultural competence integration into the nursing curriculum. Information drawn from a descriptive qualitative study utilizes focus groups of American undergraduate and doctoral nursing students. The findings of this article could be strategically applied to frontline providers in Canadian outpatient HFDMPs for developing culturally sensitive skills in care delivery. Both Canada and the United States face similar ethnic differences and associated HL challenges, especially when English is not the first language for a patient population. Students in the study created a "taskforce on cultural diversity" that drew up a consensus-based framework for integrating cultural competence into their curriculum. Likewise, in an outpatient HF network, an interdisciplinary taskforce can

examine the integration of culturally sensitive skills in patient encounters. Providers must feel safe to freely discuss topics in depth and to "provide spontaneous reactions, reflect on personal experiences, verbalize opinions, and hear the experiences of others and compare" (Sumpter & Carthon, 2011, p. 44).

Ingram (2011) uses a literature review of English publications from the 1990's to the present and discusses how holistic nursing care of ethnic and marginalized patient groups can be enhanced by utilizing HL and cultural sensitivity techniques together to influence positive health care outcomes for these vulnerable populations. Campinha-Bacote's Process of Cultural Competence Model is advanced as a framework that providers can use when working with diverse population because of "its practicality in diverse and international healthcare settings" (Ingram, 2011, p. 696). Ingram (2011) praises the PCC framework for including cultural and HL assessments in patient encounters to develop individualized and holistic care plans (Ingram, 2011). This practice project aligns with Ingram's view and advances a notion that in HF outpatient settings patients' self-care could increase when a program is tailored to patients' needs, cultural beliefs, and HL levels.

A pragmatic view of "universally applicable standards of practice for culturally competent care that nurses around the globe may use to guide clinical practice, research, education, and administration" (Douglas, et al., 2011, p. 317) is put forward in the literature. This concept aligns with the earlier call for universal HL precautions in service delivery already discussed in this paper. Douglas, et al., (2011) draw on principles of social justice that uphold fair and equal access and participation in social,

educational, economic, and health care opportunities for individuals and population groups. An international web-based survey with responses from seventy-eight hospital nurses in sixteen countries yields twelve standards of practice for culturally competent nursing care, (see Appendix H).

Providers have to view cultural competence as a "dynamic, lifelong learning process" with the aim of "preventing overgeneralization and stereotyping" patients (Moore, Moos, & Callister in Douglas, et al., 2011, p. 320). A framework like the PCC can keep providers current in culturally sensitive assessments, effective communications, and respectful behaviours with diverse patient groups. Through ongoing education, and encounters culturally competent nurses are able to "recognize the harmful effects of ignorance, hate, ethnocentrism, prejudice, and bias" (p. 322) on the health outcomes of their patients. Providers can learn to develop their own internal and external resources for culturally sensitive updates and practice. For example, providers in a HF outpatient clinic can develop and provide culturally sensitive listening, attentive body language, eye contact, modesty, touch, silence, dress, and particular provider gender as a means to enhance communication patterns and expressions (Douglas, et al., 2011). The authors claim that a multilevel approach at the "individual, organizational, group and societal levels" is needed in developing and sustaining cultural competency (p.327). Randomized control trials are needed to test the efficacy of "culturally congruent interventions" in reducing disparities in health outcomes. There is little published literature that compares HF experiences and outcomes among groups of patients of diverse ethnic backgrounds. Few studies specific to BC address the effects of population diversity in outpatient HF

care; however, we can draw some inferences from an Australian study because demographically Australia holds similarities to Canada (Davidson, et al., 2007). As chronic conditions are increasingly managed in community settings a shift towards appreciating diverse health beliefs and health seeking behaviours is occurring.

The Australian study uses an exploratory, observational design to investigate health pat-terns, information needs and the adjustment process for people of different ethnicities living with HF in Australia. The methodology involves an integrative literature review and qualitative data collection from interviews and focus groups. This study asserts that though people's attitudes, values, beliefs, and behaviours about health and illness are influenced by their respective cultures; individual variances in attitudes and beliefs do prevail. According to this study, important factors influence health and illness experiences of different ethnicities in the following ways: family and kinship ties influence treatment choices; the family doctor is seen as the gatekeeper to the health care system; and, religious and traditional beliefs influence how people process their thoughts and feelings about death and dying, especially older people Davidson et al., (2007). Interestingly, the study's population feared and dreaded cancer more than HF, which raises implications, for how HF information delivery can impact patients' choices in viewing and managing this health condition, particularly when information delivery is being done in outpatient environments. Davidson, et al., (2007) support a notion that culture does influence how patients can perceive health, illness, and self-care behaviours in relation to HF. Thought-provoking insights for providers to consider when developing cultural competence is patients' experience of forced or voluntary migration,

generational migration phases, inherent genetic predispositions to health issues, and beliefs around health care seeking, access, and equity. Cultural practices that can conflict with evidence-based HF self-care practices are notions of promoting rest in contrast to exercise, forsaking HF as a sign of aging that cannot be altered, putting off seeking early medical attention when needed, and not disclosing complete information between family members. The latter poses a "significant challenge" for providers in discussing self-care strategies and treatment options (Davidson, et al., 2007).

In family interviews tensions of perceived burden and associated responsibility on adult children can emerge. Adult children of immigrant HF patients who are non-English speaking may opt not to disclose too much information to their parents in order to protect them. Practices of keeping HF information undisclosed can prevent open communication and can enable exacerbations of HF symptoms. In other situations, placement of parents into nursing homes can be perceived as adult children failing their parents, which gives rise to feelings of guilt and resentment towards parents. Community focus groups demonstrate a willingness to share personal experiences but individuals struggle with speaking about their HF experience (Davidson, et al., 2007). Findings from focus groups include: importance of cultural practices for elders, comfort with own cultural group sessions, letting children's needs supercede own needs, perceiving that people are sent home from hospital too soon, feeling awkward about men and women sharing the same ward when in hospital, and feelings of increased isolation and dependency as people get older. Davidson, et al. (2017) assert immigrants diagnosed with HF face coming to terms with the seriousness of their HF condition and "adjusting to this [condition] in a society

and health care system to which they are not accustomed" (p.55). Providers ought to keep an open, inquisitive mind, and be willing to foster an understanding of the power of cultural competence as one of the components for sustaining HF self-care behaviours in a diverse HF outpatient population. Incorporating an "appraisal of [patients'] social, psychological, existential, and cultural needs" (p. 59) into care plans can assist with ensuring these important areas are assessed as part of implementing a holistic-biomedical HFDMP.

Diversity training is growing in health care education. Shared insight into cultural patterns of diverse ethnic groups can enhance service delivery to these groups. For instance cultural views of extended family, male decision-making, and belief in fate in Latin population groups can affect how these patients make choices for their treatment plan. In contrast, East Asian groups who are concerned with 'saving face' try to avoid answering sensitive questions directly. Providers working with this group can successfully perform complete assessments by asking sensitive questions in a manner that helps people reveal personal information while still maintaining personal dignity. For some groups of patients, the stigma of mental illness might mean they report on this condition by elaborating on the physical state without speaking about their emotional state (Horwitz, Sonilal, & Horwitz, 2011).

Maghani in Phillips, et al (2012) further suggests that racial or ethnic concordance could become part of a "larger construct that combines patient, provider, and system variables" (p. 1086). Some of the variables could be mastery of another language, length of patient-provider partnership, complexity of health or illness and

where the patient is situated – for example in an inpatient versus an outpatient setting. An ethno-centric patient-provider partnership could be a beneficial strategy worth considering in an outpatient HF setting for select patient groups, and depending on availability of providers who can be matched in such partnerships. However, cultivating a broader understanding in cultural sensitivity is probably more feasible, with more reliable access to culturally sensitive partnerships. Patients' perceptions of sensitivity on the part of providers can influence health care satisfaction, regardless of racial or ethnic concordance. Patients give weight to feeling they can trust their provider, being treated with dignity and respect, and feeling understood which are characteristic of interpersonal sensitivity (Phillips, et al., 2012).

A retrospective analysis of 2001 data collected from over 2,000 survey-respondents involves a patient sample of mixed American races in an age group of 50 years or older. The age 50 criteria stems from earlier literature that suggests "ethnic populations experience the aging processes and disparities in health at [an] earlier age than mainstream populations" (Phillips, et al., 2012, p. 1082 In view of the early age health disparities and aging onsets perceived with ethnic groups, it could be beneficial to incorporate cultural sensitivity in all health care settings. Perhaps the notion of universal cultural sensitivity can be expanded upon to extend the use of health care resources in more appropriate, cost saving ways at earlier stages of any disease development through health promotion. This means that cultural sensitivity in the delivery of health care to younger members of ethnic societies could potentially reduce long term complications of chronic illnesses as this patient population ages.

Future research needs to look at perceived health service satisfaction and motivation for health maintenance among diverse young and old populations (Phillips, et al., 2012). Further examination about the concept of cultural competence is needed to develop effective implementation and evaluation techniques that can enhance its function. Demands are being placed on health care providers to behave in culturally competent ways in order to help alter or eliminate "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific populations groups" (Giger, et al., 2007, p.97). Research suggests that cultural competence is attainable, but there is little evidence about the efficacy of specific mechanisms to utilize this treatment modality consistently. Further investigations into the phenomenon of cultural sensitivity and its impact on health out-comes are needed.

Conclusion

HL and cultural sensitivity could enhance outpatient HF self-care and produce sustainable positive health outcomes for these patients. A "revolving door" effect could be avoided in B.C.'s HF network strategy, and improved HF outcomes could be realized sooner if attention is given to the HL and cultural contexts of patients who are asked to follow HF self-care guide-lines. The provincial HF strategy aims to impact HF population health upstream by promoting self-care on an outpatient basis. It seems the government assumes that providers can deliver evidence-driven HFDMPs effectively and that HF patients will be able to adapt to self-care strategies easily. However, shortfalls in self-care practices can occur because HF patients have variable HL levels, and cultural

challenges. Providers can be ineffective in communicating about HF self-care knowledge with these patients in a busy outpatient environment.

There is a perceived advantage to patients being in control of evidence-driven HF self-care, and skillful assessment and application of HL and cultural sensitivity approaches by providers can ensure that HF self-care can flourish in an outpatient environment. Integrating HL and cultural sensitivity into evidence-informed self-care requires assessing patients' literacy levels, and individuals' personal values. In patient encounters, providers must convey individualized messages to HF patients that despite their HL and cultural contexts they can exercise power over HF progression. Providers must reassure HF outpatients that they will not be abandoned or set adrift in their self-care programs. Patients need to hear that providers will step in when self-care deficits (or challenges) outweigh patients' self-care agencies. Tailored interventions for self-care learning can engender precise application of HF self-maintenance strategies. This could help reduce self-management issues as exacerbations of HF symptoms are less likely to happen.

HFDMPs are designed to systematically support a HF outpatient self-care culture in which the HF patient learns to become a self-care agent, guided by an interdisciplinary team of health care providers. Part of self-care agency requires self-reporting HF symptoms, journal writing, story-telling, and reviewing pharmacy refill records. A reporting tool like the SCHFI can be used as a "gold standard" for measuring and communicating patients' self-maintenance, self-management, and self-confidence behaviours. The SCHFI outcomes of interest in HFDMPs can point patients and

providers in the direction of achievable targets. Careful assessments of patient characteristics in regards to HL and cultural values can help providers tailor strategies that can fit into HF patients' lives. HL screening tools like the S-TOFHLA can be used with caution, since patients may be subjected to time constraints that can hinder their performance and give poor interpretations of their HL capabilities. The NVS is a three minute HL screening tool that could be used in busy outpatient HF clinics to assess patients' HL levels as a sixth vital sign.

The use of "universal precautions" for HL requires using plain words and the teach-back method could prove helpful with information sharing in all patient encounters. Providers can use a five-step HL assessment process and learn to acknowledge signs of inadequate HL using effective communication strategies, see Appendices C, D, and E.

The impact of patients' cultures on their HL levels requires assessment by providers, as well. However, providers must first be willing to assess and reflect on their own personal cultural biases and how these influence their clinical practice in patient encounters. Campinha-Bacote's Process of Cultural Competence can help providers' become culturally sensitive through its constructs of awareness, skill, knowledge, encounters, and desire see Appendix F. Practice with diverse patient encounters is an imperative to becoming more culturally sensitive. Providers can practice culturally sensitive interview skills that tap into the patients' world view and social organization, see Appendix G.

HL and cultural sensitivity is a necessary investment for health care training institutions. Health care professionals need adequate skills in HL and cultural sensitivity

to complement their clinical practice. Universal cultural competence is a practice method like universal HL precautions that providers can strive to use unconditionally and skillfully in patient encounters in order to prevent disparities in health care delivery and outcomes. For B.C.'s diverse outpatient HF adult population it is important to avoid "cookie cutter" medicine and service delivery. Providers need to carefully assess patients' HL levels and cultural values and beliefs about their HF, and ability to engage in self-care. Utilizing evidence-informed tools and techniques in a respectful way can reorganize HF self-care. This practice project provides a background literature review that could be used in future regional or provincial studies in evaluating the efficacy of HFDMP strategies towards QOL outcomes for HF outpatients.

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Appendix A
Literature Matrix

AUTHOR	PUB YR.	COUNTRY	TYPE OF PAPER	STUDY DESIGN	THEMES OR CONCEPTS	DEPENDENT VARIABLE	INDEPENDENT VARIABLE	SAMPLING METHOD	DATA SOURCES	FIT
Allingham	2012	Canada	Secondary	not applicable	none	not applicable	not applicable	not applicable	not applicable	LOW
Anderson, et al.	2003	U.S.A.	Secondary	Literature Review	Culturally competent healthcare	Cultural competence in healthcare systems	5 interventions as outlined in article	Electronic searches for studies evaluating interventions to increase cultural competence	Specific selection criteria as explained in article	MEDIUM
Baker	2006	U.S.A.	Secondary	not applicable	Conceptual construct of individual capacity, health-related print capacity, oral literacy, and health outcomes.	not applicable	not applicable	not applicable	not applicable	HIGH
Barnason et al.	2011	U.S.A.	Secondary	Integrative literature review	Self-care theory, self-care model for patients with HF, self-determination theory, Health Education Model, theory of Unitary Human Beings Person-Environment process, Social Cognitive Theory	HF self care	cognitive-behavioural strategies, evidence-based education and counselling	Papers from 2000 - 2010 with following: use of non-pharmacological intervention to improve HF self care, control and treatment	Electronic databases, and manual ancestry searches	HIGH
Bostock	2011	U.K.	Journal Artcile	not applicable	Understanding how the heart works.	not applicable	not applicable	not applicable	not applicable	HIGH
Boyde, et al	2009	Australia	Primary	Qualitative	Focusing HF education as identified by patient needs	not applicable	not applicable	Purposive	Questionnaire and Interviews	MEDIUM
Britz & Dunn	2010	U.S.A.	Primary	cross-sectional, descriptive	SCD needs assessment can augment QOL for HF pts, by informing specific educational interventions that can build self-care confidence	QOL with HF	SCD, specific educational interventions, and self care confidence	convenience	Patient interviews, charts, SCHFI scale, MLHF qustionnaire	HIGH

Appendix A cont'd

Cameron et al	2009	Australia	Secondary	Literature Review	Orem's theory and definition of self-care & naturalistic decision-making framework.	not applicable	not applicable	Papers from 1980 - 2009. Studies selected have HF-specific measures and report reliability and validity.	Electronic databases using search terms: patient compliance, statistics and numerical data, CHF, heart disease, heart failure, congestive, self-care, health surveys, self-management.	HIGH
Campinha-Bacote	2011	U.S.A.	Secondary	none	PCCDHS is an ongoing process towards culturally conscious healthcare delivery	none	not applicable	not applicable	not applicable	HIGH
Chaudhry, et al.	2011	U.S.A.	Secondary	Restrospective analysis of pre-intervention data from a RCT	differences between black and whites with HF in HL and access to outpt care	HF HL and access to HF care	Race, demography, comorbidity, social support, socioeconomic status	Participants recruited from 33 community-based cardiology practices across the US between 2005 and 2009.	Baseline interviews within 30 days of hospital discharge.	HIGH
Chen et al.	2011	U.S.A.	Primary	cross-sectional, descriptive	Health literacy and self-care	Heart failure	Health literacy and self-care	convenience	S-TOFHLA, SCHFI	HIGH

Appendix A cont'd

Coleman	2011	U.S.A.	Secondary	descriptive lit review -based on material presented at the Institute for Healthcare Advancement Ninth Annual Health Literacy Conference, May 2010.	none	not applicable	not applicable	not indicated	Review of medical, nursing, and allied health professions literature specific to teaching health literacy principles	MEDIUM
Coleman, et al.	2008	U.S.A.	Charter on Health Literacy	not applicable	core principles for development of health literacy curricula	not applicable	not applicable	not applicable	not applicable	MEDIUM
Cross	2011	United Kingdom	Secondary subjected to double-blind review and antiplagiarism software	not applicable	nurses educating patients to self-care	not applicable	not applicable	not applicable	not applicable	LOW
Davidson, et al.	2007	Australia	Primary	Exploratory observational	not applicable	not applicable	not applicable	Convenience sample	Electronic data bases for literature review. Focus group interviews with patients, families, providers.	HIGH
Dennison et al.	2011	U.S.A.	Secondary	descriptive, comparative	none	HF self-care and outcomes	Health literacy and HF knowledge	172 HF inpatients approached and asked to participate.	DHFKS and SCHFI questionnaires	HIGH
De Von, et al.	2007	U.S.A.	Primary	Descriptive	Review conceptsof reliability and validity in healthcare literature	not applicable	not applicable	CINAHL, MEDLINE, and PsycINFO - articles of past 5 years	Electronic data bases using key words and concepts associated with reliability and validity	MEDIUM

Appendix A cont'd

Douglas, et al.	2011	U.S.A.	Secondary	none	Cultural competence informed by Social Justice and Human Rights can reduce inequalities in health outcomes.	none	none	not applicable	not applicable	HIGH
Dykes & White	2011	U.S.A.	Secondary	not applicable	not applicable	not applicable	not applicable	PubMed search for English-language articles published 1980 - 2010.	Search words: culturally competent care education, cultural sensitivity, healthcare disparities, healthcare quality, medical education.	LOW
Evangelista, et al	2010	U.S.A.	Primary	Literature Review	Health literacy princples	HF Care	HL	not clear	not clear	MEDIUM
Foronda	2008	U.S.A.	Secondary	not applicable	not applicable	not applicable	not applicable	CINAHL, Academic Search Elite, ERIC, ProQuest, PAIS, Google, PsychInfo published 2000 - 2005	Search words: cultural sensitivity, or culturally sensitive	LOW
Geiger	2001	U.S.A.	Commentary	not applicable	not applicable	not applicable	not applicable	not given	not given	LOW
Giger, et al.	2007	U.S.A.	Journal Artcile	not applicable	Expert panel on Cultural Competence	not applicable	not applicable	not given	not given	MEDIUM
Hebert, et al.	2010	U.S.A.	Primary	Single center study of HF patients in a HFDMP	not applicable	survival benefit	HFDMP Program	Convenience Sample	Clinical records	MEDIUM
Heinrich	2012	U.S.A.	Primary	descriptive, cross-sectional design for a pilot project	HL, and assessment using NVS in primary care settings	HL	Education level, ethnicity/race	Recruitment at urban outpatient diabetic clinic. Interpreter used for Spanish-speaking participants.	demographic survey, assessment of patients via interpreter, and use of NVS	MEDIUM

Appendix A cont'd

Heydari et al.	2011	Iran	Primary	descriptive correlational	perceived threat and challenges to self-concept and adherence to HF regimen	Adherence to HF regimen	self-concept	convenience	2 questionnaires, Cognitive Perception of Cardiovascular Healthy Lifestyles and Adherence	HIGH
Horner, et al.	2004	U.S.A.	Publication of expert panel consensus	use of personal knowledge and knowledge of literature of national experts chosen by Office of Minority Health	Interventions most likely to improve cultural competency of providers	not applicable	not applicable	not applicable	Brainstorming, casual literature review`	LOW
Horvat, et al.	2011	Australia	Secondary	Literature Review	Cultural competence and outcomes.	Patient, provider, and system outcomes	Cultural competence education interventions for providers.	Electronic data base searches of studies that include RCTs, cluster RCTs, and quasi-RCTs.	Strategic searches of databases from their start date to present, and with no language restrictions.	HIGH
Horwitz, et al.	2011	U.S.A.	Secondary	Literature Review	Ways in which issues of diversity can be addressed in health care	none	none	not given	not given	MEDIUM
Ingram	2011	U.S.A.	Secondary	Literature Review	Relationship between HL and CC	Healthcare services for minorities	Health literacy and Cultural competency	Peer-reviewed Secondarys in English from 1990's to present.	Data base search, keywords Campinha-Bacote, cultural competence,healt h literacy, nursing.	HIGH
Kaan	2005	Canada	Secondary	not applicable	Defining HF and basic biomedical care	not applicable	not applicable	not applicable	not applicable	LOW
Langer	2008	U.S.A.	Discussion paper	not applicable	not applicable	not applicable	not applicable	not given	not given	MEDIUM

Appendix A cont'd

Macabasco-Oconnell, et al.	2011	U.S.A.	Primary	cross-sectional analysis	HFQOL, HL, Self-care, self-efficacy	HFQOL	HL, self-care behaviours	selection criteria, pts approached at regular outpt appts and asked	Patient interviews.	HIGH
Majumdar, et al.	2004	Canada	Primary	RCT	Providers' cultural awareness can shape patients' health outcomes	Patients' health outcomes	Cultural sensitivity training for providers.	Convenience sample of nursing and home-care providers; volunteer patients.	5 questionnaires, 1 scale	MEDIUM
Manning, et al.	2010	U.S.A.	Secondary	Retrospective hospital chart reviews	Approach to acute HF management	not applicable	not applicable	Convenience sample	Hospital records	LOW
Morton	2012	U.S.A.	Journal Artcile	none	Interprofessional and transcultural learning builds cultural competence.	not applicable	not applicable	not applicable	not applicable	LOW
Osborn, et al.	2007	U.S.A.	Primary	2 separate comparison studies in 2 separate locations	Comparison between NVS and REALM, and NVS and STOFHLA	NVS	REALM and STOFHLA	Recruited from 2 patient care clinics	Interviews and HL tests	HIGH
Phillips, et al.	2012	U.S.A.	Primary	Restrospective analysis of 2001 survey	Relationship between Pt-provider ethnic concordance and health outcomes	none	none	Random Digit Dialing	25-minute telephone interview in multiple languages	MEDIUM
Polit & Beck	2008	U.S.A.	Text Book	none	not applicable	not applicable	not applicable	not applicable	not applicable	HIGH
Riegel et al.	2009	U.S.A.	Secondary	not applicable	Update on SCHFI	not applicable	not applicable	not applicable	not applicable	HIGH
Robinson et al	2011	U.S.A.	Primary	prospective study as part of ongoing RCT	pros and cons of STOFHLA	HF HL	S-TOFHLA timelimits	not clear	patient selection criteria, Mini-cog, STOFHLA with and without time limit.	HIGH

Appendix A cont'd

Schim, et al.	2005	U.S.A.	Primary	Cross-sectional descriptive	Examine variables associated with cultural competence among providers in Ontario and Michigan.	Cultural competence in providers.	Prior training in cultural competence, and higher educational attainment.	Convenience sample of providers employed at urban hospitals in Ontario and Michigan. Sample of providers participated on voluntary basis.	written surveys that took 20 - 30 minutes to complete	HIGH
Seto et al.	2011	Canada	Primary	cross sectional, correlational	self-care and QOL, determinants and barrieres	QOL with HF	self-care	convenience	SCHI and Minnesota living with HF questionnaires and semi-structured interviews	HIGH
Sumpter & Carthon	2011	U.S.A.	Primary	Qualitative, descriptive	Integrating Cultural Competence into curriculum	not applicable	not applicable	Convenience sample	Focus group discussions and audio recordings that were transcribed	HIGH
Tierney et al.	2011	United Kingdom	Tertiary	Systematic review synthesizing qualitative studies	altered body-sense, negative emotions, adjusting to altered state, interpersonal influences	HF	exercise adherence	Papers from 1980 onward, written in English, mixed methods only if qualitative findings separate from quantitative, HF patients viewpoint and any discussion about exercise or activity	electronic databases, gray literature, first 100 Google hits and select websites	HIGH
Timmins & Horan	2007	Ireland	Secondary	Literature Review	Self-care Deficit Nursng Theory	Coronary nursing care	SCDT	Papers from 2001 - 2006, published in English. Inclusion criteria: any reference to SCDT in the context of coronary care and/or cardiac-related conditions.	Electronic search of CINAHL, and PubMed using key words Orem [and] nursing [and] coronary care.	HIGH
Whitemore & Knafl	2005	U.S.A.	Secondary	Literature Review	Distinguish integrative review method from other review methods	not applicable	not applicable	not given	not given	HIGH

Appendix B
Primary and Secondary Validity Criteria (Based on Whittemore et al.'s Framework)

Criteria	Definition
PRIMARY CRITERIA (Essential)	
Credibility	Confidence in truth of the data and interpretations of them
Authenticity	Extent to which a range of different realities are shown
Criticality/Integrity	Evidence of critical appraisal of key decisions in an inquiry ensuring that interpretations are based on data
SECONDARY CRITERIA (Supplementary)	
Explicitness	Clear methodology given, biases identified, and evidence presented in support of conclusions and interpretations
Vividness	Salient themes from the data highlighted
Creativity	Challenges to traditional thinking with new insights and perspectives
Thoroughness	Adequate sampling, and data completeness
	Findings show connections with other studies and study contexts
	Findings reflect respect and concern for different cultural, social, and political contexts of those being studied

Source: (Polit & Beck, 2008, p. 540 – 541)

Appendix C: Summary of Rationale and Core Principles of HL

Rationale	Principles
Research and evaluation needed to examine relationship between health outcomes and individuals, communities, systems, and cultures.	• Sound methodological approaches required in developing evidence base for HL interventions. • HL curricula are based on current evidence for interventions.
HL curricula written for all people, regardless of educational level, culture or literacy skills. All people will benefit from improving HL of individuals, health system, personnel, and health system.	• Use participatory approach, involving intended audience at all stages of HL curricula and evaluation tools development. • Curricula and evaluation tools should be based and designed to advance HL theory. • Curricula and tools should be based on same understanding of HL, even though target groups of individuals and health conditions differ. • Consistency is needed to allow comparison across contexts.
HL encompasses more than plain language, reading, writing, numeracy, and effective communication between health professionals and the public. • HL includes ability to navigate differences between cultures of the health system and the public. • HL means being aware of and minimizing power imbalances between health system and public. • Health literate professionals and systems allow and encourage patients to feel welcome and empowered to ask questions; deliver information in ways that people can use; proactively take steps to prevent ill health and provide treatment to all people in need.	• HL curriculum should integrate approach to social, cultural, political, economic and environmental determinants of health • Curriculum should consider skills and abilities associated with individual HL and the cultural, social, economic, and policy issues associated health systems.

Appendix D
Addressing Low Health Literacy

Step 1: Recognize that Health Literacy is real and may compromise patient care.

Step 2: Identify patients at risk for low Health Literacy.

Step 3: Screen patients who are at risk.

Step 4: Document learning preferences in patient records.

Step 5: Integrate strategies to facilitate health education

Possible Signs of Low Health Literacy

Patients who: State they forgot their reading glasses

Claim the lighting is poor

State they will read instructions later

Point to words as they read

Lift the paper closer as they read

Fail to follow medication instructions

Miss appointments

Fail to follow through with tests and referrals

Evangelista, et al., (2010, p. 13).

Appendix D
Effective Communication Strategies

Slow down communication with patients.

Use common language and fewer medical terms.

Use or draw pictures.

Use analogies or stories to personalize the message.

Limit information given in each interaction and repeat instructions.

Focus on key messages.

Use a ‘‘teach back’’ approach to confirm patient understanding.

Include family, significant others, or friends in discussions.

Be respectful, sensitive, and kind.

Source: Evangelista, et al., (2010, p. 13).

Appendix F
Cultural Competency in Healthcare
Delivery: Have I ASKED Myself The Right Questions? © (Campinha-Bacote, 2002

Awareness: Am I aware of my biases and prejudices toward other cultural groups, as well as the existence of racism and other "isms" in healthcare?

Skill: Do I have the skill of conducting a cultural assessment in a culturally sensitive manner?

Knowledge: Am I knowledgeable about the worldviews of different cultural and ethnic groups, as well as knowledge in the field of biocultural ecology?

Encounters: Do I seek out face-to-face and other types of sacred encounters with individuals who are different from myself?

Desire: Do I really "want to" become culturally competent?

Appendix G

Understanding patient's world view and social organization

1. What do you call your problem? What name does it have?
2. What do you think caused it?
3. When do you think it started?
4. What does your sickness do to you?
5. How severe is it? Will it have a long or short course?
6. What do you fear most about your sickness?
7. What are the chief problems your sickness has caused for you?
8. What treatment should you receive? What are the most important results you hope to receive?

Source: (Kleinman in Langer, 2008).

Patient Cultural Status Exam (Pfeiffering in Langer, 2008)

1. How would you describe the problem that has brought you here?
2. Who in the community and your family helps you with your problem?
3. How long have you had this problem?
4. Do you know anyone else with it?
5. Tell me what happened to them when dealing with this problem.
6. What do you think is wrong with you?
7. What might other people think is wrong with you?
8. Tell me about people who don't get this problem.
9. Why has this happened to you, and why now?
10. What do you think will help clear up this problem?
11. If specific tests, and=or medications are listed, ask what they are and what they do.
12. Apart from me, who else do you think can make you feel better?
13. Are there therapies that make you feel better that I don't know about?

Appendix H
Standards of Practice for Culturally Competent Nursing Care: 2011 Update

Standard	Description
Standard 1: Social justice	Professional nurses shall promote social justice for all. The applied principles of social justice guide nurses' decisions related to the patient, family, community, and other health care professionals. Nurses will develop leadership skills to advocate for socially just policies.
Standard 2: Critical reflection	Nurses shall engage in critical reflection of their own values, beliefs, and cultural heritage to have an awareness of how these qualities and issues can affect culturally congruent nursing care.
Standard 3: Knowledge of cultures	Nurses shall gain an understanding of the perspectives, traditions, values, practices, and family systems of culturally diverse individuals, families, communities, and populations they care for, as well as a knowledge of the complex variables that affect the achievement of health and well-being.
Standard 4: Culturally competent practice	Nurses shall use cross-cultural knowledge and culturally sensitive skills in implementing culturally congruent nursing care.
Standard 5: Cultural competence in health care systems and organizations	Health care organizations should provide the structure and resources necessary to evaluate and meet the cultural and language needs of their diverse clients
Standard 6: Patient advocacy and empowerment	Nurses shall recognize the effect of health care policies, delivery systems, and resources on their patient populations and shall empower and advocate for their patients as indicated. Nurses shall advocate for the inclusion of their patient's cultural beliefs and practices in all dimensions of their health care.
Standard 7: Multicultural workforce	Nurses shall actively engage in the effort to ensure a multicultural workforce in health care settings. One measure to achieve a multicultural workforce is through strengthening of recruitment and retention effort in the hospital and academic setting.
Standard 8: Education and training in culturally competent care	Nurses shall be educationally prepared to promote and provide culturally congruent health care. Knowledge and skills necessary for assuring that nursing care is culturally congruent shall be included in global health care agendas that mandate formal education and clinical training, as well as required ongoing, continuing education for all practicing nurses
Standard 9: Cross-cultural communication	Nurses shall use culturally competent verbal and nonverbal communication skills to identify client's values, beliefs, practices, perceptions, and unique health care needs.

Appendix H cont'd

Standard 10: Cross-cultural leadership outcomes	Nurses shall have the ability to influence individuals, groups, and systems to achieve outcomes of culturally competent care for diverse populations.
Standard 11: Policy development	Nurses shall have the knowledge and skills to work with public and private organizations, professional associations, and communities to establish policies and standards for comprehensive implementation and evaluation of culturally competent care.
Standard 12: Evidence-based practice and research	Nurses shall base their practice on interventions that have been systematically tested and shown to be the most effective for the culturally diverse populations that they serve. In areas where there is a lack of evidence of efficacy, nurse researchers shall investigate and test interventions that may be the most effective in reducing the disparities in health outcomes.

Source: (Douglas, et al., 2011, p.318)