The Influence of Heart Failure Patients' Values on Self-Care Decision-Making

By

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Abstract

Heart failure (HF) is a common, costly, disabling and deadly syndrome. It places a considerable burden on Canadian society and on patients, their families, and the health care system. Self-care behaviors are essential to effective HF management. Adherence to some self-care recommendations, however, is selective – that is, patients may choose certain recommendations but not others. They may be influenced by many factors, such as patients' belief systems. A core component of these systems, which may influence behaviors, are patients' values.

Values have not been clearly defined or explored in relation to HF self-care behaviors. As a consequence, practical approaches to and models of the self-care decision-making process lack adequate incorporation of individuals' values. As such, this project seeks to understand the nature and influence of HF patients' values in relation to self-care decisions.

As human behavior is best studied in natural situations, critical realism (CR) was selected the ontological foundation for this project. The lens of CR reveals that individuals live in open complex ("real world") systems with behavior being influenced by the interplay between different factors in these systems. Using CR helped me to design and choose appropriate approaches for this project in order to generate fundamental knowledge concerning HF patients' values, and to develop models.

To provide the full context and description of my dissertation project, this dissertation offers insights into the background and rationale for the study of patients' values and self-care behavior in HF patients. This thesis also aims to present manuscripts of three interrelated studies, which are: a concept analysis of HF patients' values, a systematic review to synthesize evidence, and a qualitative study to examine how HF patients' values influence their self-care decision-making.

For the first study, a concept analysis of “patients’ values”, I reviewed 121 papers and books. Based on this work, I defined the concept of patients’ values as meaning *core beliefs*, which are abstract and subjective in nature, and perceived as very significant to individuals. Values function within a system and the priority of values can be changed under certain circumstances. The second paper reports a mixed-methods systematic review. From this work, two models are proposed: the first conveys how patients’ values are involved in self-care decision-making, while the second addresses what types of patients’ values are involved in self-care decision-making. In the third paper, I identify two types of values, functional and emotional, which influence self-care decisions in HF patients with NYHA class II and III. Each type of values relates to self, others, and health professionals. In addition, this study sheds light on five ways that values are involved in patients’ prioritization of their values in order to make self-care decisions.

These three studies may enable nurses and other health professionals to understand HF patients’ values, and how those values affect self-care decision-making. Furthermore, the studies may inform future research to develop self-care models and approaches that enable healthcare professionals to help HF patients in their self-care decision-making based on their values.

Preface

The first study in this dissertation project is a concept analysis study entitled: “Patients’ Values: An Evolutionary Concept Analysis.” This study will be submitted to the journal *Nursing Inquiry*. For this study, I conducted a comprehensive search strategy with the assistance of a librarian, reviewed the literature, analyzed the data using Rodgers’ evolutionary model, and wrote up the results. This paper will be co-authored by Dr. Alex Clark and Dr. Jude Spiers who made substantial contributions to improve the quality of the all steps of this study and consequently the rigor of the results.Dr. Kyle Whitfield, and Dr. Kara Schick Makaroff also provided important advice and guidance with respect to this paper.

The second study was a mixed-methods systematic review entitled: “How do patients’ values influence heart failure self-care decision-making?”, and was published in the *International Journal of Nursing Studies*. I reviewed all of the literature and analyzed the data and wrote the paper for publication. The paper was co-authored by Dr. Alex Clark, who is an expert is conducting both qualitative and quantitative research. All steps of this study were supervised and reviewed by Dr. Clark, and his inputs into their development was substantial.

The third study was a qualitative study entitled “making sense of heart failure patients’ views on their value-based self-care decisions.” Data used for this study was part of a major study, led with principal investigator Dr. Laurene Sheilds (also involving Dr. Clark), entitled “Living with Life-threatening Illness: Narratives of Liminality.” For this study, I was involved in developing questions that directly sought to understand patients’ values. I was closely involved in providing definitions for the concepts of self-care and patients’ values for the study and discussed the two elements with a research assistant prior to conducting interviews with HF patients. From January to December of 2016, I also participated in the two-hour team meetings that were conducted regularly via Skype every other week at the University of Victoria focusing on the research. My involvement in the analysis of the transcripts was related to considering the function of patients' values – the specific concern of the current, focused analysis, upon which I commenced work during 2016. I analyzed the data for this focused study after the completion of an ethics review by the Health Research Ethics Board. Research ethics approval was received from the University of Alberta Research Ethics Board, The Human Ethics Research Online (HERO) for this third study. (ID. Pro00062959), on February 26, 2016

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Chapter 1: Background and Rationale

This chapter provides the background and the rationale for the entire dissertation. First, I describe the nature and significance of the burden imposed by Heart failure (HF) on individuals, family members, and health-care systems. Then, I will focus on self-care behavior as a means of improving HF outcomes but also the challenges of engaging in these behaviors. These challenges will be discussed in relation to the variety of influential factors, of which patients' values will be emphasized as a factor that is mostly overlooked in the literature. The philosophical and historical uses of the basic concept of patients' values will then be examined, before four prominent health behavior models, and their lack of focus on values are discussed. Finally, the aims of this study are outlined along with details of my position within critical realism, the meta-theoretical framework that is used to guide the thesis.

In many records, people who are receiving care or engaging in care are referred to as *patients*, *clients*, or *consumers of health care*. For the purpose of this thesis, recognizing this divergence, I select the term *patients,* which has been the most conventional term through years of research in the literature around heart failure.

The Significance of Heart Failure

Heart Failure (HF) is a worldwide public health priority (Krul et al., 2010; Pilote et al., 2007; Toback & Clark, 2017). It is a common, disabling, and deadly syndrome that significantly influences the quality of life of patients and their families (Albert, Trochelman, Li, & Lin, 2010; Butler, 2008; Juenger, 2002) and results in high costs for patients, their families, and the health care system (McMurray et al., 2006; Krul et al., 2010; Pilote et al., 2007). In Canada, HF affects more than 1% of the adult population (Chow et al. 2005).

HF places a heavy burden (Albert et al., 2010; Butler, 2008) on both individual with HF (Clark et al. 2008; Krul et al., 2010) and health-care systems (Pilote et al., 2007; Robertson et al., 2012)**.** The syndrome causes a wide variety of symptoms, including: exertional breathlessness, fatigue, signs of fluid retention as well as signs associated with the underlying disorder (Figueroa & Peters, 2006; McMurray et al., 2006) and has various possible aetiologies (Jones, 2006; Figueroa & Peters, 2006). It can be difficult for HF patients to distinguish these symptoms from those arising from other comorbid conditions such as lung disease or diabetes) (Albert et al., 2010; Butler, 2008). More importantly, severe HF symptoms, such as increased shortness of breath, swelling of legs, fatigue, weight gain, mental confusion, and even unconsciousness (Figueroa & Peters, 2006; McMurray et al., 2006), frequently require hospitalized treatment preferably from specialialists able to stabilize symptoms quickly (Albert et al., 2010; Butler, 2008).

Burdens on Individuals with HF

Despite the heavy burden HF places on health systems and economies, arguably, it's greatest burden falls on patients themselves – via high rates of mortality, reduced quality of life, and frequent rehospitalisation (McMurray & Stewart, 2003; McGurk, 2010; Musekamp et al., 2017).

Mortality. HF reduces life expectancy: the median survival time after an HF diagnosis is 1.7 years for males and 3.2 years for females (Pilote et al., 2007). Increasing age is also linked to reduced survival time – patients aged over 85 have a median survival time of 1.5 years (Gathright, Goldstein, Josephson, & Hughes, 2017). In spite of current medical therapy, for patients hospitalized for HF, the rate of mortality is still around 33% in one year (Canadian Heart Failure Network [CHFN], 2013).

Quality of life. HF is also a very challenging disease to live with. HF impairs quality of life more than other chronic medical disease, including: angina, myocardial infarction, hypertension, arthritis and chronic bronchitis (Hobbs et al., 2002; McMurray & Stewart, 2002). HF has a substantial negative effect on all dimensions of quality of life including basic activities of daily living (Juenger et al., 2002) and sexual activity (Levine et al., 2012; Mandras, Uber, & Mehra, 2007). This wide and negative effect on quality of life often contributes to depression (McMurray & Stewart, 2002; Musekamp et al., 2017) or even suicide (Showers, & Ryff, 1996) possibly due to the gap between individual values and constrained daily life (Eckersley, 1999). Further study is needed of these gaps between individual values about their lifestyles and how those values can pragmatically be achieved in particular in different circumstances (J. Spiers, personal communication, March 15, 2014).

Burden on the Economy and Health Care System

HF is one of the greatest health care challenges of the 21st century (Braunschweig, Cowie, Auricchio, 2011; McMurray & Stewart, 2002; Robertson et al., 2012). The Heart and Stroke Foundation of Canada (HSFC) declared in 2003 that the rates of hospitalizations for cardiovascular disease, with the exception of HF, were decreasing and 40,000 hospitalizations were anticipated for the year 2005. However, research in 2005-2006 identified 54,333 (Public Health Agency of Canada, 2009) hospitalizations for HF, significantly greater than the number projected. Given continuing growth in the elderly population (Pilote et al., 2007), 80000 hospitalizations in Canada are estimated by 2025 (HSFC, 2003). This comes at a price, with a reported cost burden of $1.4 to $2.3 billion annually in Canada (Shibata, Nilsson, Hervas-Malo, Jacobs, Tsuyuki, 2005). More specifically, between 2000 and 2006 in Alberta there was a 60% increase in total costs of HF (Krul et al., 2010). This growth, as Krul et al. (2010) note, represents an increase in care costs from 11% to 15%, and in physician costs from 15% to 18% of the total costs of HF. Consequently, annual health care costs for HF are considerable and increase over time, placing a significant economic burden on the health care system and society. This relates both to the cost of treatment and care (e.g. frequent rehospitalisation) as well as to the demands on family members or informal caregivers (Braunschweig et al., 2011; Robertson et al., 2012; Omar et al. 2007).

A Key Constituency: The Aging Population

These individual effects are challenging for all HF patients, and are particularly significant for the elderly, a large and growing segment of that population defined as people aged 60 years and over (World Health Organization [WHO], 2016).

The role of aging in the study of HF patients is crucial and needs to be better understood. First, HF is common in the elderly population because major changes in cardiovascular structure, function, and physiology are associated with aging (Nadruz et al., 2016; Rich, 1997). Other age-related changes in the urinary, respiratory, and nervous systems and the pharmacokinetics and pharmacodynamics of almost all drugs are also associated with development of HF in the older population (Azad & Lemay, 2014; Rich, 1997). It is estimated that half of all HF cases occur in 6% to 10% of the population aged 65 years or older (Joseph, 2009).

Second, this elderly population continues to rise. The number of people aged 65 and over was 5.4 million in 2013; approximately 5-10 million more elderly people are anticipated by the year 2063 (Statistics Canada, 2015). The major reasons for the increased prevalence of HF in the elderly population are as follows:

1. Medicines have improved survival rates from myocardial infarction (Dargie, 2001; & Hellerman, et al., 2003). Indeed, the improved treatment protocols for conditions such as acute

myocardial infarction, hypertension, diabetes, renal failure, and metabolic syndrome may trigger the development of systolic and diastolic ventricular dysfunction (Braunschweig, Cowie, & Auricchi, 2011).

2. Life expectancy for Canadians at birth, as another influential factor, is expected to continue to increase, reaching 81 years for men and 86 years for women in 2041, from 75.8 years and 81.4 years in 1997, respectively (Health Canada, 2002).

In parallel with increasing life expectancy, and consequently with an increasingly aging population, the incidence and prevalence of HF continue to rise. Subsequently, as noted, the burden of HF in the elderly population and society is likely to grow (Canadian Heart Failure Network [CHFN], 2013). Given these rises, self-care will have an increasingly important role in relation to HF.

Self-Care Behavior as a Means of Improving Outcomes

Self-care has a major role to play in reducing the HF burden. I will now address the nature, implications and negative costs of poor self-care. Modern healthcare seeks to improve patients' health and minimize negative effects of HF on the physical, emotional, psychological and social well-being on both HF patients and caregivers, via a combination of self-care practice, medications, and the use of implantable mechanical assistive devices or heart transplantation surgery (Cowie & Zaphiriou, 2002; Remme & Swedberg, 2001; Krum, Jelinek, Stewart, Sindone, & Atherton, 2010). The term *self-care* has been used interchangeably over the last decade with others, including: self-management, lifestyle management (Cowie & Zaphiriou, 2002), and non-pharmacological management (Remme & Swedberg, 2001; Krum et al., 2010). This concept has been defined in a variety of ways.

For the purpose of this study, self-care is defined as a *complex process which involves decision-making and action taking based on intrinsic factors (knowledge, skills, values and capability) and extrinsic factors (e.g. socioeconomic status, social support, personal relationship, and continuity and quality of care)* (Clark et al., 2008; Siabani, Leeder, & Davidson, 2013; Thomas, 2011; Kadal et al, Clark et al., 2008). Thus, individuals, families, and communities must participate in this process to lead optimal care in a stable and altered situation, to prevent and limit the detrimental health consequences of HF, and to enhance overall health and clinical outcomes. Although I recognize that patients are always embedded in the community, by definition, self-care is always performed by the individual at the individual level.

This definition views self-care as a complex process influenced by various social and contextual factors as well as individual factors (e.g. values, experience, and reactions to HF) (Hill, 2011; Freydberg, Strain, Tsuyuki, McAlister, & Clark, 2010). Self-care behavior, like other kinds of behaviors, cannot exist separate from the influence of individual and contextual factors. Individual factors include bio-behavioral (e.g., attitudes and self-efficacy), physiological (e.g. cognition status, physical functioning, fatigue, and comorbid conditions), demographic (e.g. age, culture, and gender), personal (e.g. knowledge of HF and its symptoms, previous experience, skills, attitudes, and self-efficacy), and psychological factors (depression and anxiety). Contextual factors influencing self-care behaviour pertains caregivers' support or other social variables (e.g. health-care system; culture) (Clark et al., 2009; Dickson & Riegel, 2008; Dickson, Tkacs, & Riegel, 2007; Moser, & Watkins, 2008).

Components of self-care. In an unpublished qualitative systematic review that I conducted under the supervision of Dr. Alex Clark, I found that the components of self-care in HF are multifaceted. Although, in some contexts, self-care behavior indirectly refers to observable actions (Mann, 2010, Jarresma, 2000), this review found three types of self-care behaviors: cognitive (Carlson et al, 2001; Riegel et al., 2004), behavior (Jaarsma, Abu-Saad, Dracup, & Halfens, 2000), and developmental behavior (Table 1.1). Importantly, examples from the developmental and cognitive categories (e.g. thinking, feeling or perceiving) may be less easy to observe but are vital self-care behaviors (Schumacher, Stewart, & Archbold, 1998; Saarmann, Daugherty, & Riegel, 2000). Research to improve self-care behavior in HF patients at the cognitive, practical, and developmental levels has been done these are still critical goals for research as self-care adherence remains poor (Ambrosy et al., 2014).

Table 1.1

Types of Self-Care Behavior in HF

Types of Self-Care Behaviors	Example
Cognitive Behaviors	Decision-making, problem solving, goal setting, and generating strategies
Practical Behaviors	Taking medication, seeking help from health professionals, restricting salt consumption, regular physical activity, communicating with health care professionals, restricting alcohol consumption, monitoring weight and fluid intake, monitoring the body for troublesome signs of worsening HF, using energy conservation techniques, and reducing stress
Developmental Behaviors	Improving knowledge, skills, and self-efficacy

Benefits of HF self-care. HF self-care is an efficient way of improving HF outcomes (Jaarsma, Stromberg, Martensson, & Dracup, 2003; Lee, Tkacs, & Riegel, 2009) by minimizing the increased levels of norepinephrine (NE) and angiotensin II (ANG-II) (through medication adherence) and minimizing activation of certain neurohormonal systems (through dietary sodium restriction) (Lee, Tkacs, & Riegel, 2009). Conversely, poor outcomes in HF patients often result from lapses in self-care behavior (Lee, Tkacs, & Riegel, 2009). Evidence also suggests that better HF self-care improves health status domains (e.g. general health, social functioning) and enhances the quality of life (Riegel, Dickson, & Lee, 2011).

The impact of HF self-care is not only associated with the patients' health status, but also with other aspects of their lives. For example, effective HF self-care significantly reduces hospitalization rates (DeWalt et al., 2006; Lee, Moser, Lennie, & Riegel, 2008) and high costs to patients, their families and society (Lee et al., 2008). These impacts have been examined in the randomized controlled trials (RCTs) conducted as part of a program on clinical and financial outcomes for patients with HF; the results indicate a reduction in care costs in the USA for HF patients who were supported in their self-care activities. However, variance in the amount of savings per patient per year, from US $6,985 (Krumholz et al., 2002) to US$2,823 (Koelling, Johnson, Cody, & Aaronson, 2005) and US$1,500 (Cline, Israelsson, Willenheimer, Broms, & Erhardt, 1998) has been reported. These savings result from reducing readmissions and in-hospital costs (Krumholz et al., 2002; Koelling, Johnson, Cody, & Aaronson, 2005; Cline, Israelsson, Willenheimer, Broms, & Erhardt, 1998). Self-care also increases patients' self-reported quality of life (Seto et al., 2011; Wang, Lin, Lee, Wu, 2011) and 5-year survival rates by 50% (McAlister, Stewart, Ferrua, & McMurray, 2004; Jovicic et al., 2006; DeWalt et al., 2006; Lee, Moser, Lennie, & Riegel, 2008). HF self-care is then crucial to reducing the economic, social, and health-related burdens of HF.

Effects of poor self-care behavior. Poor self-care is common and has a number of negative consequences. 40% to 60% of HF patients are non-adherent with respect to taking medications (Wu, Moser, Lennie, & Burkhart, 2008). Recent studies have found that 38% to 76% of patients were adherent to their medication regime (Riegel et al., 2011; Nieuwenhuis, Jaarsma, van Veldhuisen, & van der Wal, 2012). Approximately only 10% to 40% of patients follow advice about low-sodium diet (Ni et al., 1999; Lainscak et al., 2007). Adherence to daily weighing (34%-85%) and exercise (48%-64%) is also poor (Nieuwenhuis, Jaarsma, van Veldhuisen, Postmus, & van der Wal, 2012).

In general, low adherence is related to the high complexity of HF self-care (Clark et al., 2009; Riegel et al., 2009). Interventions have had mixed effects on reducing hospitalizations (Clark & Thompson, 2012). Communication between patients and health care providers is frequently poor in terms of effective communication skills, sufficient time providing information to patients and their family care givers as well as listening to patients (Garland, & Stajduhar, 2013; Ratcliffe, 2007). This suggests more understanding of the nature of HF self-care and how to best improve this is needed.

The challenges of improving self-care behavior. Self-care behavior is complex and challenging (Clark et al., 2009), because it has many components (Clark et 2014; Artinian, Magnan, Christian, Lange, 2002; Ni et al., 1999). To engage in effective HF self-care, patients need to acquire knowledge, skills, and ability to analyze their symptoms and situations, and to make effective decisions and act accordingly (Moser, Watkins, 2008). However, in order to improve adherence and consequently improve outcomes, simply being knowledgeable about HF self-care is insufficient (Clark, et al., 2008; Davis et al., 2012) due to the influence of many individual and contextual factors in HF self-care decision-making that may mediate, moderate, or even prevent effective self-care actions.

Influential factors are important in HF self-care. Determinants of self-care behaviors in HF patients have been extensively studied in many parts of the world – notably the United States, but also such regions as Europe, Asia, the Middle East and South America (Khatibzadeh et al., 2013). Five major categories in this classification are characteristics of HF, socio-demographic factors, competency-based factors, psychological factors, and belief system (Table 1.2).

Table 1.2

Determinants of Self-Care Behaviour

Determinants	Elements	Example
Characteristics of HF	***Symptoms and characteristics***	Acute dyspnea is associated with more timely treatment seeking (0.5 days) than non-acute dyspnea (dyspnea on exertion). However, oedema, increased circumference of abdomen, weight gain, nocturnal symptom onset, fatigue, and cough predict longer delay in care-seeking for HF symptoms (Gravely-Witte, Jurgens, Tamim, & Grace, 2010).
	Functional Class	Advanced HF functional class (classes III and IV) is associated with poor self-care behavior (Siabani et al., 2013).
Socio-Demographic Factors involving a combination of social and demographic factors (Merriam-Webster Online Dictionary, 2014)	***Age*** Aging populations have more difficulty in carrying out, distinguishing, and interpreting symptoms as a result of aging related factors (Riegel et al., 2010)	***Cognitive Status***: Impaired cognition and loss of depth perception are linked to poor HF self-care (Hajduk et al., 2013). ***Comorbidities*****:** HF patients with comorbidity experience difficulty in managing HF as well as in differentiating HF symptoms from other disease symptoms and normal aging. The complicated treatment regimen confuses the patients and leads to an ineffective self-care (Zavertnik, 2014). ***Activity intolerance*****:** Activity intolerance and balance impairment interferes with capability to do activities including self-care activities (Riegel et al., 2007; Siabani et al., 2013).

		Sensory impairment: Sensory impairment including decreased vision, impaired visual contrast, hearing impairment, and sensory perception can reduce the patients' ability in learning, symptom recognition, and carrying out self-care (Riegel et al., 2010). ***Sleepiness:*** Poor sleep influences daytime behavior comprising self-care behavior (Riegel & Weaver 2009).
	Sex/Gender	Women were found to be highly at risk patients and were more in need of support for psychosocial health and self-care (Thomas, & Clark, 2011).
	Education level	Patients with adequate literacy had higher self-efficacy ($p < 0.01$), and higher prevalence of self-care adherence ($p < 0.001$) than those with low literacy (Macabasco-O'Connell et al., 2011).
	Social situation	Patients had particular difficulty in remembering or finding low sodium food choices at social events (Heo et al., 2009). Workplace may also influence self-care decisions (Feydberg et al., 2010)
	Social support	Social support or support of others includes self-care, emotional, financial, social and psychological support. Such support is provided by family care givers, in particular partners, to community support and is an important influence on outcomes (Gallagher, Luttik, Jaarsma, 2011; Clark et al., 2014; Strachan et al., 2014).
	Costs	Health care costs and drugs costs can be a significant economic barrier to adherence to self-care behavior (Siabani et al., 2013).
Competency-based Factors Factors underlying successful self-care performance	***Knowledge*** The truth that an individual is objectively certain about (Simons-Morton, McLeroy, & Wendel, 2012)	HF knowledge has been found to correlate with higher prevalence of self-care adherence ($p < 0.01$) (Macabasco-O'Connell et al., 2011).
	Skills	Self-care skills along with knowledge are required to enable adherence in HF patients (Dickson & Riegel, 2009).
	Experiences	Prior experiences about HF symptoms links to timely self-care decision-making (Siabani, Leeder & Davidson, 2013; Moser & Watkins, 2008).
Psychological Factors	***Personality***	Patients with Type D personality appeared to be less likely to visit or consult effectively with health-care professionals (Oosterom, 2012).

Factors that are defined into the three areas of personality, emotions and coping styles	***Emotional factors***	Emotional factors such as feeling like a burden to others, as well as stress, anxiety, or depression affect symptom interpretations and responses (Siabani et al., 2013; Falk, Patel, Swedberg, & Ekman, 2009).
	Coping strategies	Adaptive and maladaptive coping strategies (e.g. avoidance and denial) can promote or hinder, respectively, self-care adherence in HF patients (Siabani et al., 2013).
Belief systems Includes different level of thought in terms of importance, stability, and influence	***Perception*** Interpretation of information (Simons-Morton, McLeroy, & Wendel, 2012)	Patients' perception of self-care effects self-care decision-making (Goodman et al., 2003).
	Values Core beliefs and the leading factor in the decision-making process (Rokeach, 1973; Feather, 1988)	Patients' values are crucial and must be understood and be integrated in the care plan (Clark et al., 2014).
	Beliefs Thought that is considered to be true (Simons-Morton, McLeroy, & Wendel, 2012)	Beliefs as facilitators: holding the view that medicines and self-care activities helps to treat their heart (Percival, Cottrell, & Jayasinghe, 2012), or medicines were "necessary" (Cottrell et al., 2013). Beliefs as barriers: not trusting health professionals (Siabani et al., 2013) or being "overmedicated" (Cottrell et al., 2013).
	Attitudes An individual's positive or negative evaluation about a particular behavior.	Positive attitude toward remote monitoring influence in self-care behavior (Seto et al., 2010).
	Confidence The degree which someone trusts him/her self	Self-care confidence has been found to be a predictor of self- care management (Salyer, Schubert, & Chiaranai, 2012).
	Perceived behavioral control An individual's perception about ease or difficulty of acting a given behavior (Ajzen, 1991)	The perceived probability that performing self-care improves outcome influences self-care decision-making (Peters-Klimm et al., 2013).
	Perceived self- efficacy Beliefs in one's capabilities to perform a particular behavior.	One's perceived ability to perform HF self-care is associated with adherence (Peters-Klimm et al., 2013).
	Locus of control Personal beliefs about what are the causes of the events in one's life	Patients with internal locus of control believe that their health can be controlled by their own activities, while people with an external locus of control believe that their health problem is as a result of others, or can be controlled through

		luck or by others such as doctors (Rydlewska et al., 2013). Patients believe that many of the causes of their illness were outside their control (Goodman et al., 2013).
	Subjective norm An individual's perception about engaging or not engaging in a particular behavior, which is influenced by social pressure (e.g., from parents, spouse, teachers) (Ajzen, 1991).	The support and encouragement of healthcare providers and important others can positively influence a HF patient to comply with a low-sodium diet regimen (Welsh et al., 2013).

While a variety of the influential factors have been identified as predicting effective HF self-care behaviors and improve outcomes (Riegel et al., 2011; Heo, Lennie, Moser, & Okoli, 2009; Savard, & Thompson, 2009), the precise determinants of self-care adherence remain unclear (Riegel et al., 2011). Efforts to enhance patients' self-care knowledge, for example, have not yielded consistent improvements in HF outcomes (Macabasco-O'Connell et al., 2011). Such incongruous results raise the following questions: When patients are physically and mentally capable of making decisions and complying with self-care recommendations, what makes an individual acquire knowledge and then after gaining this knowledge, what makes people in different circumstances use and act on their knowledge and adhere to recommended self-care behaviors? Why do patients' attentions toward their disease change over time (Paterson, 2001)? This may reflect an individual's own belief system, particularly values –an area that has not received attention in the nursing literature (Appendix B). In the context of HF, considerable research has been devoted to studying patients' attitudes and beliefs, but not their values. Scholars have not attempted to fully and explicitly explore the role of values in relation to their structures, underlying mechanisms, and functions – for example, whether they act as a mediator or a moderator.

Belief systems as moderating or mediating variables?

A *moderator* is defined as “an independent variable that affects the strength and/or direction of the association between another independent variable and an outcome variable” (Bennett, 2000, p. 416). For example, age was addressed as a potential moderator in the relations between coping strategy and coping effectiveness in HF patients (Pozehl et al., 2014). By contrast, a *mediator* is a variable that explains how and why a strong relationship exists between an independent variable and an outcome variable (Bennett, 2000). For example, self-care confidence was found to be a mediator in the relationship between perceived social support and self-care maintenance in HF patients (Cené et al., 2013).

There is surprisingly, little literature examining whether patients’ values function as a moderator or mediator of self-care behaviour. Beliefs and attitudes, however, have been identified as moderators of the influence of self-care on outcomes (Kohnke, Cole, & Bush, 2014; Pozehl et al., 2014); yet researchers have reported inconsistent results regarding the moderating effects of different beliefs on outcomes. For example, while irrational health beliefs were not found to be associated with adherence to an exercise programme, will to live was associated with adherence (Anderson, 2015). Furthermore, a sense of confidence – that is, the belief that one can execute self-care behavior – has frequently been examined, and has been found to be a moderator of the relationship between self-care management and outcome (Riegel & Dickson, 2008). Such beliefs, however, do not seem to moderate the association between non-adherence and negative perceptions (concerns about side effects). Age and gender as demographic factors were also found to be moderators of the effect of perception on adherence and outcome (Spitzer, Bar-Tal, & Ziv, 1996).

In sum, while self-care confidence – as a type of belief – has been widely investigated as a mediator/moderator of self-care management (Riegel & Dickson, 2008), other important elements, such as values, have been overlooked. Due to limited research and divergent results within the available research, further work is required to examine whether each of the elements of belief systems (values, beliefs, and attitudes) are mediators or moderators and how the relationship between values, beliefs, or attitudes and self-care decisions is moderated by demographic characteristics such as age and gender.

The lack of sufficient focus on patients' values may be related to the tenets, constructs, and philosophical foundations of the behavioral models that underpin those studies. Thus in the next section, I revisit the philosophical and historical uses of the basic concept of patients' values; a concept that is evident in Florence Nightingale's nursing theory (focusing on improving physical, psychological moderating, and social environments to enhance nursing care (Powers & Knapp, 2010).

Philosophical and Historical Overlap of Values

Theories from different disciplines view the concept of values through specific lenses. I will now address the philosophical and historical overlaps in various underlying conceptualizations of the concept of *values*, and will consider the influence of those various views on the nursing literature. Nursing is a profession and discipline that has central guiding values: there are values held by the profession, by patients, and by stakeholders (e.g. health-care professionals and institutions). Nursing draws from a diverse philosophical understanding of what value means (Flanagan, 1998, Risjord, 2010). Such reliance is grounded in three main causes: a) Theories from other disciplines that can also contribute to the knowledge and practice of nursing to varying degrees. Indeed, although theorists in different disciplines may have divergent perspectives on values, they may address aspects of the concept based on useful disciplinary lenses and theoretical standpoints; b) Knowledge produced in nursing must be in line with a focus on the holism concerning patient care (Ellis, 1968; Risjord, 2010); c) Synthesising and adapting knowledge, which derive from other disciplines is also compatible with the values of nursing (Risjord, 2010).

Thus, insights from different disciplines can contribute to developing comprehensive nursing care theories, which view and explain the complex interplay of biological, psychological, behavioral, and societal aspects of nursing clients/patients (Risjord, 2010). This is particularly apt in relation to individuals' values which are involved in all areas of human life and in different realms (Edel, 1993). In seeking to understand this interplay, I may benefit from value theory (Hirose & Olson, 2015). In recent decades, social and behavioral scientists, including theorists in marketing, psychology, sociology, medicine, and anthropology, through their disciplinary lenses have contributed considerably to developing value theory in terms of theorizing the nature of attributes, including structure, types, and the impact of values. Generally, values across disciplines are recognized as a type of belief that guides an individual's decisions and then their behavior; however, our understanding of these values might need to be modified, given that in other disciplines they may have been constructed based on different theoretical perspectives that are not applicable in the context of nursing. In the social science disciplines, for example, values are usually investigated in relation to behaviors such as societal voting, which is a social and political behavior, as opposed to health behaviors, which are mainly self-related behaviors. Such different contexts may influence the construction of a definition and cause ambiguity within literature, which relies upon various definitions from different disciplines. [1]

Concepts derived from other fields may inspire useful discussions, but could produce confusion too, when they are brought into the context of nursing. For instance, values in the discipline of economics and marketing are also intimately tied with objective values (e.g. monetary value) and subjective values (e.g. maximizing consumer satisfaction) (Fleischmann, Oard, Cheng, Wang, & Ishita, 2009). This lens has affected nursing research in various ways. The scope of application of subjective values in the discipline appears to have changed over the past century, as researchers have come to question whose values are to be considered: those of health professionals or patients. Indeed, two different ways of focusing on subjective values, based on different approaches to the question of patients' autonomy, have been practiced in these disciplines (Reich, 1982; Hanssen, 2004; Cody, 2013). Traditionally, a *paternalistic* approach, which focused on the values of health-care professionals, has dictated practice – that is, although the health professionals' values focused on patients' wellbeing, the patients' own values were ignored or subjugated to those of the professional. However, this practice began to be questioned in the 1970s through the introduction of patient-centered (autonomous) care (Bleakley, 2014). Generally speaking, one of the key principles of patient-centered approaches (Provision of care that is responsive to the patient values [Hirsch & Abernethy, 2012]) is responsiveness to the values of patients, families. In marketing, values are viewed as a perception of the mind in relation to its desire toward an object through the process of giving worth to an object, and it is a

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[1] Risjord proposed two types of concept analysis, scientific/theoretical concept analysis and colloquial concept analysis. Theoretical concept analysis clarifies conceptual materials that nurse theorists will rework for their own ends" (Risjord, 2009, p.682). While theoretical concept analysis places an emphasis on the literature, colloquial concept analysis seeks to clarify the concepts that are used in a specific community (e.g. nurses). However, this typology has been criticized on the grounds that the link it suggests between theory, concept, and reality is too simple and linear, and that knowledge and context are interdependent (see Duncan, Cloutier, & Bailey, 2009).

matter of an individual's desire (Simmel, 1900). Such a description has been frequently evident in the nursing and medical literature, which studied the use of the value-centered care approach by providing treatment options to patients.

Other different theories of value are grounded in the interrelated disciplines of sociology, psychology and anthropology, and in the work of Kluckhohn (1951), Allport (1961), Kohn and Schooler (1969), and Rokeach (1973). These theorists attempt to understand and also predict human behavior and have had a major influence on the conceptualization of the concept of values. Generally, values are defined by these scholars as individual traits that comprise cognitive and affective components and rooted in social systems that guide our behavior (Rokeach, 1973, 2000; Schwartz, 2012). In this school of thought, values are beliefs that are abstract and are not based in one’s preference towards a specific object. Thus, in the health-related research relying on these definitions, patients’ values are viewed as abstract. The focus and the results of these studies differ from studies that focus on patients’ values at the point of selecting one treatment option.

Importantly, some of the theories of the psychosocial disciplines hold the premise that values can predict behaviors; however, other theories postulate that attitudes and beliefs rather than values toward a particular object (e.g. disease, treatment) can predict behavior. This is the main tenet of the Theory of Reasoned Action (TRA) (Appendix A, Figure A1) (Ajzen & Fishbein, 1980), the Theory of Planned Behavior (TPB) (Ajzen, 1988) (Appendix A, Figure A.2), the Common Sense Model (CSM) (Leventhal, Meyer, & Nerenz, 1980) (Appendix A, Figure A.3), and the Health Belief Model (HBM) (Rosenstock, Strecher, & Becker, 1988) (Appendix A, Figure A.4). These theories collectively are called *expectancy value theories* because they assume that individuals behave in accordance with their values. That said, these theories can be criticized on the basis that in spite of their general designation as expectancy value theories, they fail to address individual values nor do they guide us in conceptualizing values or explaining how values predict a given behavior in a systematic or replicable way (Cameron & Leventhal, 2003; Miller, 2003). Furthermore, while attitudes and beliefs in relation to disease and treatment are proposed to predict behavior, this is not guaranteed (Brandes & Mullan, 2014). Such failure is evident from a meta-analysis of the effectiveness of the application of the CSM in predicting patients' adherence to self-management recommendations (Aujla et al., 2016). This limitation was also revealed in a survey study in relation to the ability of the TPB to predict the uptake of human papillomavirus (HPV) vaccination among young women (Gerend, & Shepherd, 2012), and in a meta-analysis of the usefulness of the HBM in the prediction of positive health behaviors (Carpenter, 2010). Table 1.3 illustrates a critique of these four models. In the following section, I will critically examine expectancy-value theories.

Theory of Reasoned Action (TRA)

The TRA (Appendix A, Figure A.1) is also referred to as Fishbein's expectancy-value theory; I now address its premises and limitations in predicting behaviour. This model was developed by Martin Fishbein and Icek Ajzen (1975, 1980) to predict a person's intention to perform a behavior and to understand the underlying reasons for a person's behavioral intention based on her/his attitude towards a particular behavior and normative beliefs about the given behavior. Some researchers have expressed concerns about the limitations of the TRA in explaining "actual control" rather than perceived control among people who have less control over their health-related behaviors and attitudes (Godin & Kok, 1996). Thus, the TRA was enhanced and the new model was named the theory of planned behavior (TPB) (Ajzen, 1991).

Theory of Planned Behavior (TPB)

The TPB is similar to TRA but consists of another element of perceived behavioral control (Appendix A, Figure A.2). Perceived behavioral control indicates a person's perceptions regarding the degree of difficulty in performing a particular behavior, as well as their perception of their ability to do so. As in the case of the TRA, the main focus of the TPB is on the potential of attitudes in explaining human actions (Ajzen & Fishbein, 1980).

While these two models have been widely used in studying individual behavior, including self-care behavior, some researchers have suggested that they are not applicable for the study of behavior in an organizational context in which multiple layers and many individuals are involved in decision-making (Johnston & Lewin, 1996). Likewise, while these models may be suitable for some studies of self-care behavior, they present problems in other cases. For instance, even when a patient's attitude is positive toward self-care behavior and s/he is aware of the benefits of the self-care components to her/his health, s/he might not desire to adhere to some recommendations and might prefer to enjoy her/his life. For example, s/he may stop visiting a doctor in order to not be criticized for nonadherence, and may therefore bypass the subjective norm. In such cases a positive attitude as well as subjective norms toward self-care behavior does not motivate the person to adhere to health professionals' recommendations self-care behavior. Instead, a desire for "joy" motivates the person to choose how to behave.

Whereas, in this example, as a positive or negative belief toward self-care behavior is an attitude – the type of belief captured in the model – joy is another level of belief, a value, which is more abstract and is not directed specifically at self-care. Rather, joy is an overarching belief that guides decision-making. As such, theories of the TRA and the TPB can be criticized on the basis that they fail to address individual values and that attitudes do not necessarily link to behavior in all cases. This notion can also be supported by the results of the studies on help-seeking behavior (Han et al., 2006), sexual relationship behavior (Fenton et al., 2005; Sinha et al., 2007; Griffiths et al., 2008), and bowel cancer screening (Smith et al., 2012).

Common-Sense Model (CSM)

The Common Sense Model of self-regulation theory is also called the “parallel model”, the illness representation model or the personal model of illness and was developed in 1987 by Leventhal and Cameron. The CSM model is based on the assumption that a person is an active problem solver when a disease is perceived as a threat. This process of solving problems is proceeded through two parallel cognitive (problem-focused) and emotional (emotional-focused) pathways. Each pathway involves three stages including illness representation (or common sense), coping behaviors, and appraisal of those coping behaviors (Appendix A, Figure A.3).

Illness representation is an individual’s perceptions about an illness (with respect to the five domains of identity, timeline, cause, controllability, and consequences). This element is the key element and has been the main focus of researchers in the application of this model. Such illness perceptions are influenced by the nature of stimuli, previous experiences, beliefs, cultures, and individuals’ demographic characteristics and personality (Greaves et al., 2016; MacInnes, 2014).

Among those determinants, Leventhal (1987) has presented values as a high level of abstract goals. Nevertheless, an individuals’ values are not considered explicitly in this model. In the applications of the CSM in HF context, the focus has been on capturing patients’ illness perceptions and then identifying patients’ beliefs only at the concrete level. Accordingly, how individuals make sense of threats (HF) to their health is based on the perceptions and beliefs toward HF and its management. Understanding those beliefs is essential (Clark et al., 2014) but the number of beliefs that have been identified are so large that developing individualized tools that integrate patients' beliefs in is not feasible. Understanding patients' values as core beliefs, which are limited in number, is crucial. Accordingly, the results of a systematic review have demonstrated that care needs to take account of patients' values (Clark et al., 2014).

Another critique is related to the fundamental assumption of this theory – the perceptions of threat and fear that stimulate action. However, feeling threatened by and fearful of a disease may not always be the same. Such feelings can be ignored, altered depending on the situation or contextual factors, or changed over time. It has well been documented that some patients may fail to adhere to certain HF self-care behaviors (Marti et al., 2013; Ryan & Farrelly, 2009; Riegel et al., 2009). If the fear or the perception of the threat of the disease motivates patients' adherence, how does this model assist us to understand intermittent adherence – that is, patients' selective adherence to self-care recommendations – and the dynamic nature of the decision-making process (Maes, 2000)? For example, the difficulty of maintaining a low sodium diet around holidays such as Thanksgiving and Christmas has been frequently reported in the literature (Heo et al., 2009; Ryan & Farrelly, 2009; Riegel et al., 2009). Such circumstances highlight the role of patients' values. However, as was mentioned above, the main focus of the CSM is on beliefs, which are related to the characteristics of the disease, and fail to adequately account for individuals' values. This limits the application of this model in understanding patients' values.

Health Belief Model (HBM)

The HBM was developed by Hochbaum in the 1950s, Rosenstock, 1966, 1974, and Becker et al., 1974. The assumption underpinning this theory is that a given behavior can be determined based on psychological readiness to take action. Like the expectancy value theories mentioned, the HBM attempts to explain and predict health behaviors by focusing on the individuals' attitudes and beliefs toward a disease, benefits and outcomes of a health care behavior, barriers and strategies to comply with professionals' recommendations, and their ability to adhere to recommendations (Appendix A, Figure A. 4).

Like other models the main constructs of this model are important in understanding health behavior. However, the scope of this model fails to specify values as the core beliefs that may impact particular health behavior decisions.

Overall, these four theories of the expectancy value theories do not offer a comprehensive explanation and a theoretical starting point for the object of the main focus of my study: patient values. These discussions are summarized in Table 1.3 below.

Table 1. 3

Four prominent health behavior models

Theories/ Originator(s)	Elements/ Definition	Values/ Alternatives	Critiques Relevant to Values
Theory of reasoned action (TRA)/ Icek Ajzen & Martin Fishbei, 1975	Concrete perceptions from internal and external forces are the main elements of the TRA: ***Attitudes toward a specific behavior***: An individual's beliefs about the outcome of the behavior and evaluation of the outcome (whether it is good or bad). ***Subjective norms:*** Norms are influenced by our perceptions of others' beliefs (e.g. parents, friends, doctors, etc.). If they have a positive belief about performing the behavior, the positive subjective norm is expected, which motivates	The following terms are applied in the description of this theory but are not clearly defined: 1. *"Primary motives"* 2. *"Values and goals"* are referred to as a type of *attribute* that is associated with evaluation of behavior. *3. "Attribute evaluations"* In this theory: a. Values have not been focused as a key element.	1. Limitations of the TRA in explaining the behavior of the people who possess or feel little power over their behaviors and attitudes. 2. Inconsistency between the constructs of this model and the expectancy-values framework discussed in the text above. 3. Failure to address and define individual values. 4. Failure to capture the influence of social and cultural factors (Cameron & Eventhal, 2003). 5. Attitudes may not always be guides to an individual's health decisions.

	the individual to comply with the behavior. ***Behavioral intention:*** A function both of attitudes toward a behavior and subjective norms toward that behavior.	b. Beliefs and norms are the key elements. c. Values have not been considered as a preceding construct that effects attitude formation.	
Theory of planned behavior (TPB)/ Ajzen, 1988	Concrete perceptions from internal and external forces are the main elements of the TPB: **Behavioral beliefs**: Beliefs related to a behavior **Attitude toward behavior:** The degree to which performance of the behavior is positively or negatively valued. **Normative beliefs:** Relate to social normative pressures (from important individuals) that accept or criticize the performance of a particular behavior. **Subjective norm:** An individual's own perception of the social pressure that causes an individual to perform or not perform a particular behavior. **Perceived behavioral control:** An individual's perceptions in regard to her/his ability to enact a particular behavior. **Intention:** An individual's willingness to perform a particular behavior.	"*Values*" are referred to in passing as being associated with different beliefs" (Ajzen, 1991) but the author does not elaborate.	1. Inconsistency between the assumptions of and the constructs of this model – values are disregarded in the structure of the theory. 2. Values are not defined clearly. 3. Inconsistency between the constructs of this model and the expectancy-values framework discussed in the text above.
Common Sense Model (CSM) is also called, *1-Parallel model*, *2-Illness representation model,* *3-Personal model of illness* / Diefenbach & Leventhal, 1996; Leventhal, 1986	Key elements of this model include subjective perceptions of disease and emotional and psychological responses: **Somatic stimuli and information**: Health threat **Representation:** Individuals' perceptions about a health threat that have five attributes: 1. their identity, 2. timeline,	"Values" are equated with "goals." "Reference values" are referred to as goals that guide and evaluate the coping actions.	1. Reference values are glanced at but neither clearly clarified nor differentiated from other applied terms such as beliefs and goals. 2. The underlying fundamental assumption of this theory – the feeling of treat and fear of a given disease – may not be always the same. 3. Limitations of this fundamental assumption in explaining the behavior of people who deny the disease.

	3. cause, 4. controllability, 5. and consequences. **Coping strategies:** Developing a strategy to deal with the threat based on the individual's illness representation. **Appraisal:** the evaluation of the efficacy of the coping actions based on the outcomes.		4. Inconsistency between the assumption of and the constructs of this model. 5. Inconsistency between the constructs of this model and the expectancy-values framework discussed in the text above.
Health Belief Model (HBM) Hochbaum, 1950s; Rosenstock, 1966, 1974; Becker et al., 1974	The key elements of this model are perceptions about disease, coping strategies, and abilities: **Perceived Susceptibility:** An individual's opinion of the chances of getting a disease. **Perceived Severity**: An individual's assessment of how serious a disease is. **Perceived Benefits**: One's opinion of the effectiveness of the advised behavior. **Perceived Barriers**: One's belief in barriers to dherence to the advised behavior. **Cues to Action:** Strategies to change his/her behavior. **Self-Efficacy:** An individual's belief in one's ability to adhere to recommendations.	Values are not mentioned.	1. Inconsistency between the constructs of this model and the expectancy-values framework discussed in the text above. 2. Failure to address and define individual values.

In the social sciences, however, as I now illustrate, there has been much theoretical discussion of and empirical evidence regarding the role of an individual's values and belief systems as determinants of health behaviors.

The Roles of Values in Understanding Behavior

Many researchers have investigated individuals' beliefs in a variety of contexts, such as in studies focusing on patient centeredness, self-care behavior prediction, and self-care determinants (Cottrell, Denaro, & Emmerton, 2013; De Smedt, Denig, Van, Haaijer-Ruskamp, & Jaarsma, 2011; Molloy et al., 2009; MacInnes, 2013; Percival, Cottrell, & Jayasinghe, 2012; Sethares & Elliott, 2004; Wing ham, Harding, Britten, & Dalai, 2013). However, some of the beliefs have been referred in very general ways and others in more specific ways. While conceptualizations vary, there is general agreement that values, as a type of belief, influence behavior (Schwarts, 2012, 2008, 2006, 2002, 1992; Rokeach, 2000; Rohan, 2000, Rokeach, 1973).

Milton Rokeach (1967, 1973, & 2008) developed an extensive model of values and belief systems. Building on Rokeach's insights, Schwartz (2005, 2006, and 2012) elaborated the concept of *value priorities*, and in so doing described the structures in which values interact. According to these theorists, each person has one single belief system that includes different levels of beliefs comprising values and attitudes. Values are defined as *"an enduring belief that a specific mode of conduct or end, state of existence is personally or socially preferable to an opposite or converse mode of conduct or end state of existence"* (Rokeach, 1973, p. 5). They play an important role in an individual's belief system, in which there are countless beliefs. Several dozens of those are "values" which are very important and located in the center of belief systems. More specifically, they are abstract beliefs that form the core view of self and world (e.g., health, mature love, helpfulness, honesty, self-direction, power, security) (Rokeach, 2000; Schwartz, 2006).

On the other hand, some other beliefs, which are called *attitudes*, are peripherally located in the belief system. Attitudes are viewed as changeable and are directed toward an object and the situation in which the object is established (e.g. opinion of a patient with HF about eating out with friends at a restaurant on Christmas Day) (Lee, Tkacs, & Riegel, 2009). Attitudes are important because they influence a person to behave in a specific way toward that object (Rokeach, 2000; Schwartz, 2006). Values, however, are ultimately more important than attitudes because they play a key role in individuals' behavior by impacting attitudes (Schwartz et al., 2012; Honeycutt & Milliken, 2011; Schwartz, 2010; Bardi & Schwartz, 2003; Schwartz & Bardi, 2001; Mold, Looney, & Viviani, Quiggins, 1994). For instance, if seeking pleasure is the patient's value (which is an abstract belief), their attitude toward eating habits (a belief that is directed toward an object), and their subsequent behavior may be different than when the patient's value is being healthy.

Importantly, several researchers question "universalistic claims about context-independent attitude-value relations"; for example, Boer and Fischer (2013), in a review of 48 articles, found that contextual factors moderate the relationship between some values and attitudes (p. 1113). According to Schwartz's discussion (1992) the relationship between attitudes, values and culture is not linear. These authors, for example, simplify this relationship by investigating one specific value and one specific attitude; they thus simplify the real-world context, which is an open system, in which a mechanism functions but is subject to other complex factors (Clark, et al., 2008). Although Schwartz places emphasis on the complexity of such relationships, I argue below that they can be analyzed by understanding their underlying mechanisms.

The notion of values as being a determinant of attitudes and subsequent behavior (Schwartz, 2012; 2008; Rokeach, 2000; Rokeach, 1973, p. 18; Doll & Trokzadeh, 1991, p. 6; Durgee, O'Connor, & Veryzer, 1996) has been validated for a wide range of human behaviors in different contexts including social, family, political, sexual, religious, working, economic, shopping, parenting, and delinquency activities (Padilla-Walker, Fraser, & Harper 2012; Caprara, Schwartz, Capanna, Vecchione, & Barbaranelli, 2006; Goodwin, Costa, Adonu, 2004; Saroglou et al., 2004; Knafo & Schwartz, 2001), in deliberation and automatic decision-making processes (Ravlin, 1987; McGuire, Garavan, Saha, & O'Donnell, 2006), and in choice behavior (Feather, 1995; Sagiv & Schwartz, 1995). For instance, the acknowledgment of patients' and societal values by a physician in treatment decision-making has been identified as necessary, and key to providing patient safety and quality of care (Jenkins, Shields, Patterson, & Kee, 2007; Bauchner, Simpson, & Chessare, 2001). However, as noted above, the relationship between values and behavior is not always straightforward (Young & West, 2011; Kristiansen & Hotte, 1996) because behaviors can be influenced by contextual factors, such as normative pressure from the organization or group (Bardi & Schwartz, 2003). This relationship may also be influenced by demographic (e.g. gender and age) and clinical (e.g. severity of HF) characteristics, as follows:

1. Gender differences and prior values. The WHO defines gender as "masculine" and "feminine" with features that differ greatly between human societies. In studies of HF self-care attitudes and beliefs, gender differences have been addressed as a crucial contributor to self-care decision-making. For example, in a study situated of rural residents, conformity and tradition were prioritized values held by both males and females with HF (Clark et al., 2009). These values prohibited HF patients from seeking help from health professionals (Clark et al., 2009).

However, patients' beliefs varied by gender because of their contribution to differing experiences in different circumstances (Byrne, Walsha, & Murphyb, 2004, Schwartz & Rubel, 2005; Adams & Funk, 2012) in a wide range of countries, cultures and backgrounds (Schwartz & Rubel, 2005). For example, in a study with directors, CEOs and vice CEOs, the core values of females differed systematically from males (Adams & Funk, 2012). Furthermore, in a qualitative study female patients were identified as being more eager to continue home duties in rural settings and delay seeking help from health-care professionals when worsening symptoms occurred. (Clark et al., 2009). These results speak to the influence of gender on the type of values that people attempt to embody (Mia, 2007, Shwartz & Rubel, 2005). Ignoring the influence of gender in studies of values may lead to a lack of validity in the results and misunderstanding.

2. The influence of age. Age has been addressed as another individual factor that can impact individuals' values (Kunzmann & Baltes, 2003; Schwartz, 2006). Researchers have found that individual' values priorities change in different stages in life such as middle age and old age. This can be as a result of physical capability and changes to one's life-condition (Kunzmann & Baltes, 2003; Schwartz, 2006). Research throughout the last decade reveals that age correlates positively with "traditional" values (Schwartz, 2006; Lin, 2007), which explains why some elderly patients are less willing to change their routines. Age may therefore be regarded as a moderating variable.

3. Severity of HF. Severity of HF also provides a particular, individual circumstance in which patients' values come into play. However, there is divergent evidence regarding the ways in which severity of HF influences patients' values in relation to self-care behaviors. For example, refusing to seek help even when worsening symptoms of HF can result from placing greater importance on the value of, for example, tradition (maintaining and preserving lifelong habits and routines) rather than the value of being healthy (Clark et al., 2009; Nieuwenhuis, Maurice, Wal, & Jaarsma, 2011).

As such, values appear to drive behavior in a complex and particular way based on the different modes of behavior (e.g. decision-making, problem solving, goal setting), different kinds of values, varying structure and mechanisms and other factors such as age (Schwartz, 2006; Lin, 2005; Kunzmann & Baltes, 2003; & Forbez, 1998) and gender (Adams & Funk, 2012; Adams & Funk, 2012; Schwartz et al., 2012; Molly, Walsha, & Murphyb, 2005; Schwartz & Rubel, 2005; Crow, 1991). This complexity needs to be understood, as the function of values seems to be fundamental in the process self-care decision-making in HF patients.

Rokeach and Schwartz provide a complementary theoretical discussion about values by distinguishing values from another level of thought (beliefs and attitudes) and considering value priorities in light of the reciprocal link between values and circumstances. Again, according to Rokeach's (1973) and Schwatz's (1992, 2005, 2006) definition, *values are abstract, core beliefs that start to develop in the early years and guide the individual's behavioral practice.* However, the lack of clarification of the concept of *"patients' values"* in the HF literature is a gap that this thesis aims to fill.

Description of values in the literature on self-care in HF. In this section, I present the approaches, instruments, and models that have been applied by researchers to examine the influence of personal values on the self-care decisions made by HF patients. In addition, I critically examine their results. Over the last five years, some limited, attention has been devoted to individuals' values as a pivotal factor in the self-care decision-making process. A review of qualitative and quantitative studies (Appendix B) on belief systems and self-care in HF patients revealed interestingly that all quantitative and qualitative studies have found that belief systems influence self-care behavior (Percival, Cottrell, Jayasinghe, & Macinnes, 2013; De Smedt et al., 2012; Van der Wal et al., 2010; Clark et al., 2009; Molloy et al., 2009; Falk, Wahn, & Lidell, 2007). However, a variety of tools, questionnaires, models, and theories[2] were utilized in those studies, which has resulted in a lack of consistency. For example, some of the items in the applied tools evaluate knowledge not beliefs (Willim, Cottrel, Denaro, & Emmerton, 2013). Furthermore, as was noted earlier, the models commonly applied in the literature do not distinguish values from attitudes (e.g. common sense model (CSM), self-regulation model, the theory of planned behavior (TPB), and health belief model). In addition, although there are several tools to assess beliefs about HF and self-care, there are lack of tools to examine patients' values.

This review also revealed that in some cases authors have discussed HF self-care decision-making in the context of beliefs, attitudes, preferences, perceptions, and motivations. Although, values, beliefs, and attitudes are categorized as different levels of thought within various social studies (Rokeach, 2000, 1973, 1969; Schwartz, 2012, 2002, 1992; Feather, 1992; Rohan, 2000), the authors have not established a clear conceptual difference between these terms, nor have they focused on values as core elements of the belief system and even these elements usually have been applied interchangeably (Falk, Wahn, & Lidell, 2007; Reigel et al., 2006; Scotto, 2005). Indeed, although the results of those studies are said to be related to values,

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[2] A variety of tools, questionnaires, models, and theories such as Beliefs in HF Tool (Albert & Zellers, 2007), Illness Perception Questionnaire (IPQ-R) (De Smedt, Denig, van der Meer, Haaijer-Ruskamp, & Jaarsma, 2011; Molloy, Sniehotta, Johnston, 2009), Dietary Sodium Restriction Questionnaire (DSRQ) (Welsh et al., 2013) Beliefs about Medicines Questionnaire (BMQ) (MacInnes, 2013; Percival, Cottrell, & Jayasinghe, 2012) Looking After Your Self With HF Quesionaire (LAYHFQ) (MacInnes, 2013) The modified SECope Questionnaire (De Smedt, Denig, van der Meer, Haaijer-Ruskamp, & Jaarsma, 2011), Common Sense Model (CSM), Self-Regulation Model (De Smedt, Denig, van der Meer, Haaijer-Ruskamp, & Jaarsma, 2011,), the Theory of Planned Behavior (TPB) (Welsh et al., 2013), Information-Motivation Behavioral Skill Model (IMB) (Zhang 2012), Health Belief Model (van der WaL, 2006; Sethares & Elliott, 2004) have been utilized in these studies.

beliefs or attitudes, they represent the types of thoughts that, according to Rokeach's classification, are "beliefs".

This review reveals a significant lack of knowledge about the impact of patients' values on their self-care behavior. It also raises the question of why values, as abstract and core elements of belief systems, are absent from the HF self-care literature.

This lack of consistency appears in practice as well. For example, many of the interventions used in HF management have been arranged with limited consideration of patients' values, and have been poorly adapted to their contexts (Morales-Asencio et al., 2010; Ekman, Ehnfors, & Norberg, 2000; Dunderdale, Thompson, Miles, Beer, & Furze, 2005). Such limited consideration of patients' values is also evident in self-care-focused models.

The Concept of Patients' Values in HF Self-Care- Related Models

A variety of models in HF have focused on determinants of self-care, and their interrelationships among various determinants. Some of these models focus on the individual such as literacy, knowledge, and self-efficacy (e.g. the model of *the relationships between health literacy, self-care, self-efficacy, and knowledge in heart failure* (Chen et al., 2011), while others emphasize the process of self-care decision-making (e.g. the *self-care confidence model* (Reigel, 2008) and the *decision-making model of heart failure self-care management* (Dickson et al., 2008). However, patients' values are either absent or unclear and undefined in these models.

More specifically, the decision-making model of heart failure self-care management is a model that has frequently been applied over the last decade (Appendix C). This model has four propositions including the idea that self-care is better in patients with more knowledge, skill, experience, and compatible values (Dickson, Deatrick, & Riegel, 2008). This model suggests possible mechanisms to explain self-care management. Values and attitudes are two elements that are pointed out, but glanced over superficially. Indeed, it is not clear which “kinds” of thought ought to be considered as attitudes or values. Attitudes and self-efficacy are considered as the preliminary factors in decision-making processes but there is a lack of evidence to support this notion. In addition, there are other factors to consider such as compatibility with values. This element of the model is not also clarified.

Moreover, in light of Rokeach’s theory (1973) that attitudes are not located at the center of the belief system, the placement of values and attitudes are not in the right position in this model. These ambiguities raise questions about the applicability of this model in practice. As such, I proposed a preliminary concept map which draws on the results of the studies on values and decision-making, and the literature review on HF self-care (Appendix D). This model presents a holistic picture of the interrelationship between the influential factors and self-care decisions. The model, however, needs to be revised and enhanced based on more research. It is expected that the three interrelated studies of this larger project will achieve this goal. The interrelationship between these factors, however, is often ignored in HF self-care research. For example, knowledge of self-care has been identified in a number of studies (Strömberg, 2005; Krumholz, 2002) as a promising factor in effective self-care behavior, but this knowledge tends to be considered in isolation (Wu, Greutmann-Yantiri, Gershon, Ross, 2011).

A solid theoretical framework is needed to understand patients’ values comprehensively and to assess how circumstances and the priority of values interact to influence HF self-care behavior, which is a complex phenomenon. Drawing on a critical realist approach, I may identify these circumstances and values in order to address the existing knowledge gaps; hence, critical realism is the theoretical approach that underpins this project.

Conceptual Framework for the Dissertation Research

Critical realism provided a philosophical framework for this study. The critical realist approach allowed me to proceeds from considering the experience of an event (empirical domain) to identifying the possible structures, mechanisms, powers and tendencies that are behind the particular event (the real domain) (Dobson, 2009). These factors stem from a complex interplay of agency and contextual factors (Archer, 1995) including values and culture.

This appreciation of complexity is not evident in many approaches to the problem of self-care in HF. A large number of these studies use an overtly qualitative approach (e.g. Agard, Hermeren, & Herlitz, 2004; Riegel et al., 2007; Heo, Lennie, Moser, & Okoli, 2009) or quantitative approaches in isolation from any stated philosophy (Bennett, Milgrom, Champion, & Huster, 1997). Mussi (2013), for example, used a randomized clinical trial to determine that home visits improve self-care adherence. While a large number of studies have found the influence of several factors on self-care behavior, this study looked at self-care from just one angle (the impact of a home visit service). In such studies, researchers tend to ignore that a HF patient exists in many open systems (for example, family, community, social systems, social services, the world of work, body, and disease) and, indeed, is himself or herself an open system influenced by physiological, psychological, socio-cultural, and spiritual factors. Researchers adopting a constructivist approach likewise ignore complexity by placing excessive emphasis on individuals' subjective perspectives (Clark, MacIntyre & Cruickshank, 2007).

A critical realist framework, by contrast, provides researchers with tools to understand and analyze the complex interplay of individual and contextual factors influencing behaviors.

Importantly, a number of aspects of critical realism have been criticized by theorists, philosophers, and scholars. First, CR has been viewed as being not conceptually clear enough for a broad range of audiences (Hartwig, 2007). For example, the concepts of “critical” and “mechanism” have been questioned frequently for being unclear. Second, CR has been criticized as being methodologically weak because its methods are underdeveloped, creating “a methodologically handicapped philosophy” (Yeung,1997, p. 56). Third, in philosophical terms, CR has been challenged for failing to be “a normative philosophy of science.” (Beart, 1996, p. 513). Finally, and conversely, CR theory has been criticized for being a disguised positivist approach (Monod, 2004). However, critical realists challenge these critiques on the grounds that the critiques are narrow and polarized (Clark, Lissel, & Davis, 2008) and are related to a misunderstanding of aspects of this approach (Hartwig, 2007). Researchers have also argued that CR provides a coherent framework and a strong philosophical and methodological alternative for conducting research, either quantitative, qualitative or mixed methods, in which the mechanisms underlying a certain phenomenon are explored (Clark, MacIntyre, & Cruickshank, 2007; McEvoy & Richards, 2006).

The critical realist approach informed a study (Currie, Kidd, Clark, & Strachan, 2011) that selected a qualitative research methodology, as the most suitable to investigate the complexities of self-care behaviors in natural settings. This approach allowed researchers to gain the ‘insider’ perspectives in addition to capturing the complexity of phenomena– by understanding how individual and contextual factors congregate in complex ways to influence self-care behavior (Currie et al., 2011). Another key meta-analysis employing the CR approach expands and elaborates on these contextual factors and their implications for the effectiveness of primary and secondary prevention and treatment of coronary heart disease (CHD) programs, which took an individualized approach to prevention and treatment among patients and included one-year follow-up from community nursing staff. (Clark, MacIntyre & Cruickshank, 2007).

Drawing on CR, the relevant studies were analyzed by focusing not only on the programs but also their contexts including the setting and community. Analyzing quantitative studies through regression analysis ascertained that a key characteristic for poorer health outcomes was being a female aged over 65 years. Mechanisms were also identified through analysis of qualitative data. For example, the power of social and physical experiences of attending and the importance of context as providing continuously safe and secure opportunities to exercise were more important than the content of the program in determining the effectiveness of the program. The influence of care-providing organizations on outcomes was also explored through a qualitative evaluation. Ways of communication, professionals' role perceptions, and weakness in adapting services to local socio-economic conditions influenced quality of care.

Researchers found multiple health determinants through a variety of methods with different foci. This theoretical methodology allowed them to move from identifying simplistic results to discovering their complexity, which is underlined by the synergy between individuals, such as "users, health professionals and community health and social staff" and the local, social, cultural, organizational and geographical contexts (Clark et al., 2007, p. 527).

Study description. Given that self-care is a complex phenomenon, in order to uncover the influence of HF patients' values in the lite/rature, I seek different insights from HF patients, family caregivers, and health-care professionals and combine the results from different methods. Such a theoretical approach allows me to create a complete picture of the phenomena under study.

Generally, studies that have applied CR seeking to examine the complexity of HF self-care have revealed several benefits of this approach. At least three of these are particularly important for the present project. First, this approach provides a conceptual lens to understanding how values impact HF self-care decision-making processes. In line with this, another study utilizing CR investigated home-dialysis decision-making in people with Chronic Kidney Disease (CKD) (Harwood & Clark, 2012). The authors found that existing research is superficial due to lack of in-depth understanding and is restricted in scope when it comes to capturing the complexities of the process of decision-making around dialysis modality. Indeed, those studies were criticized for their simplified assumption, which was the dominant power of educational programme on decision-making. Rather, the influence of educational programmes is partial. The authors questioned why, despite providing education, the usage of home-dialysis is low and even diminishing. Drawing on CR, it was discussed that the process of decision-making is not dependent on one simple element (e.g. knowledge) – a view that secessionists interpret causations as a series of chain-like events. For example, intervention causes knowledge gain, then empowerment and, subsequently, a patient makes a preferred decision. This type of interpretation of causation actually fails to explain *how* educational interventions affect knowledge and empowerment. The authors discussed that decisions about the selection of the dialysis modality are generated by many interrelated factors. Patients who attend these programmes are influenced by wide societal, financial, and cultural factors, as well as by healthcare providers, programmes, and healthcare systems. For example, healthcare professionals' biases may influence patients' decision about the best modality. Similarly, in studying self-care decision-making in HF patients, the underlying individuals, social factors, and the context in which decisions are made (Harwood & Clark, 2012) are required to be taken into account. This also guides me in my concept analysis of values by selecting an approach which seeks to address all underlying factors that are related to values and influence self-care.

Second, as noted earlier, CR serves to justify the use of both qualitative and quantitative studies in the meta-ethnographic study of this project. In line with this purpose, several studies have drawn on CR as a theory that was situated between constructivists and positivists, to bridge between quantitative and qualitative methodologies and to support applying any empirical method (Scott, 2005). CR has been explored as an important theoretical foundation to support the value of mixed-methods research in providing useful evidence in a variety of fields such as management behavior (Modell , 2007), illness prevention (Sword, Clark, Hegadoren, Brooks, & Kingston), self-management in chronic disease (Kennett, O'Hagan, Cezar, 2008), behavior change (Douglas, et al., 2013), health promotion behavior (Dilworth, Tao, Shapiro, & Timmings, 2013), activity preferences (Barron, 2004), and assessment practice with relation to beliefs (Lisle, 2013). The stratified ontology of CR theory – refers to the different levels of reality including three domains of the actual (observable events), the real (underlying causal mechanisms), and the empirical (human perceptions) domains (Clark et al., 2008)– this allowed researchers to justify the "legitimate" integration of qualitative and quantitative data from single or multiple studies in information system research (Mingers, Mutch, & Willcocks, 2013), management accounting research (Modell, 2007), social inquiry (Greene, 2006), and health care research (McEvay, 2006). Given that social systems are open (a status that generates complexity), and that isolating their components is impossible, the combination of these different methodologies using intensive methods allowed them to access triangulated data and a variety of types of evidence (Modell, 2007). This provided context to uncover structures, meaning, and the mechanisms behind processes (Mingers et al., 2013; Modell, 2007; Greene, 2006; McEvay, 2006).

Third, CR is compatible with meta-ethnography in developing a theory (Audulv, Asplund, & Norberghthe, 2012). In line with this purpose, CR guided a study to develop the Self-Management Support Model by providing a lens through which the authors could understand the underlying mechanisms and the complexity of the integration of self-management into the life trajectories of individuals living with chronic illness (Audulv et al., 2012). To do so, the authors focused on patients' life circumstances, values, beliefs, needs, and ability to assimilate self-management into their work and daily lives.

Hence, within CR this proposed research is directed towards identifying how HF patients' values influence self-care decision-making. According to the CR approach, self-care behavior is likely to be influenced not only by contextual factors such as family, health professional supports, patient knowledge, and culture, but also by individual factors. As such, this approach guides us to consider how values interact with other factors to produce a decision about self-care behavior, and more importantly, the generation of patterns and descriptions of these underlying patterns (Clark et al., 2008). Applying the CR approach also optimizes data triangulation and enhances the validity of the study.

Study Purpose

Understanding how patients' values affect self-care behavior enhances my insights and sensitivity into patients' values priorities and prediction of patients' self-care behavior (Rokeach, 1973, p. 122; Schwartz, 1996; Carlos, Torelli & Kaikati, 2009). This understanding is pivotal because it is the foremost and fundamental step in improving the advocacy skills in health care professionals. In other words, this study may guide future research to assist health care professionals and others in providing different responses for patients based on their value priority instead of using one approach for all. This is in line with the first element of the Code of Ethics for Nurses, which is respecting and supporting patients' values (The ICN code of ethics for nurses, 2012).

As such, this study aims to understand:

- The current use of the concept of patients' values, and identify a definition.
- What are patients' values concerning HF self-care decision-making?
- How do patients' values influence self-care decision-making from perspectives in the literature and from patients with HF and their family caregivers?

In order to achieve these aims, three linked studies (in which the objectives are further elaborated) were conducted. The first study was a concept analysis of patients' values to clarify, characterize, and refine the concept of "patients' values". The second study was a systematic review to synthesize evidence from the literature regarding how individuals' values impact self-care behavior in patients with HF. The third study was a focused analysis conducted concurrently with a large qualitative data analysis project. It sought to examine how elements of context interact with patients' values to influence outcomes.

Overview of Studies

Each of the following three chapters presents one of the studies conducted for this thesis.

The first manuscript, which is a concept analysis study of *patients' values,* will be submitted to the *Nursing Inquiry*. The second study is a mixed-methods systematic review published in the *International Journal of Nursing Studies*. The third study was a focused analysis concurrent with a large qualitative study. All of the papers were co-authored by Dr. Alex Clark, who provided his extensive contributions to each of the steps in the three studies. The first study is also co-authored with Dr. Jude Spiers, who made substantial contributions in terms of clarifying the concept of patients' values. Dr. Kyle Whitfield and Dr. Kara Schiff Makaroff also provided important advice and guidance with respect to this paper.

The first paper was conducted because the concept of patients' values is nebulous and has not been the focus of researchers in the past. The necessity of clarifying this concept was foundational to all steps of both the systematic review study and the focused study. This concept analysis was conducted in the context of literature from a variety of disciplines using Rodgers' (2000) evolutionary concept analysis method.

In the second paper, I present a mixed-methods SR using novel approach that was applied to synthesize qualitative, quantitative, and mixed-methods data. This study is the first mixed-methods SR to investigate the influence of patients' values on HF self-care decisions. Models are developed to explain the complexity of the influence of patients' values on self-care decision-making in HF patients. The results of this study, which contribute to our understanding of the overall focus of the project, and also enhanced my preliminary knowledge, emerged from 54 included studies (30 qualitative, 8 mixed methods, and 16 quantitative**).** The third study is an interpretive phenomenological analysis of 12 interviews, which was conducted in two sites in

British Columbia and Edmonton. This study is grounded in a clear definition of patients' values that clarifies what I mean by this concept and equipped me to comprehend the reality of patients' values, as well as to ensure that the data collection process was aligned to and consistent with the objectives and outcomes of the study. The core insights, the components and the specific way of understanding this phenomenon provided by the models in SR study was taken into consideration in the third study. In other words, both the first and second studies empowered me to capture all aspects that are involved in the HF self-care decision-making process.

Chapter 2: Patients' Values: An Evolutionary Concept Analysis[3]

Abstract

This paper analyzes the concept of patients' values across different disciplines. Clarification of the concept of patients' values is pivotal because respecting and supporting patients' values as a standard of ethical conduct is widely recognized as being crucial for nurses. Despite emphasis on this foundational concept in the scholarly literature, this concept often has been used interchangeably with other terms or deemed to be considered as a self-evident and simply overlooked. Such a lack of clarity and appropriate use of the concept is notable in theories, approaches, and intervention guidelines. This study sought to understand the key elements of the concept by investigating its use in theoretical and empirical literature from different disciplines. It found that values are core beliefs that function in hierarchical systems; however, in the context of disease, the priority assigned to values may change. This is important, given that they play a foundational role in health-related decisions. Although values may be related to the self or the social context, they are influenced by both intrinsic and extrinsic needs and forces, and generally guide decisions according to their abstract nature. The attributes of the values, moreover, may vary according to the context of the disease, and according to whether the disease is physical or mental.

Introduction

Nursing values holistic practice that is tailored to individual circumstances. This fundamental goal has often been the focus of nursing research, which has sought to understand the contributions of patients' values to three aspects of care: a) the sense of confidence, efficacy, and satisfaction, and the alleviation of suffering; b) choices and decisions that are inconsistent

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[3] This study will be submitted to the journal *Nursing Inquiry* and is formatted according to the style required by the journal.

with adherence with health-care recommendations; and c) protection of patients' rights, specifically autonomy and security. This line of inquiry is consistent with a principal element of the ICN Code of Ethics for Nurses (2012) – that is, respecting and supporting patients' values.

Translating patients' values into practical nursing care accordingly is crucial. The concept of *values* is thus very significant for and in nursing and has been frequently employed in nursing literature, theories and models (Hartweg, 1991; Dickson, Deatrick, & Riegel, 2008). However, despite the plethora of articles focusing on how it is used, the meaning of values is seldom made explicit. The term *values* tend to be used interchangeably with several other terms such as *beliefs* and *preferences*. This issue has also drawn attention when these accompanied terms are employed to express a wide range of ideas across the different studies; for example, from abstract forms (e.g. joy) to very specific forms (e.g. I don't believe that these medications are effective). Such a lack of clarification may stem from an assumption that the meaning of the term *values* is self-evident. Large numbers of diverse theoretical and colloquial definitions, however, do exist in the literature.

Nurses may be unable to specify the precise meaning of values, and this concept needs definition. This is crucial in order to investigate how such knowledge in the context of individuals with disease has been or can be modified or synthesized in nursing. Values are also a central concern in practice, which is also divergent, and nurses as a professional group have to be responsive to societal needs in a way that reflects societal values and concerns, and fulfills their social mandate. Such goals can be achievable when research and practitioners are "on the same page" in terms of the concept of values.

Accordingly, the aim in this paper is to explore the range and scope of conceptualizing and defining patients' values in the nursing and health-related literature. Given the need to better understand patients' behavior, such as self-care, the scope of this review is restricted to identify the attributes, antecedents, references, and consequences of patients' values. This paper will consider each of these features in turn, after first reflecting on the approach and method used.

Concept Analysis

There are three main causes for conceptual weakness of the term *values* as it appears in the nursing research: a) vagueness around the concept; b) interchangeable use of the concept with other terms, without distinguishment (e.g. *values*, *attitudes,* and *beliefs*); and c) conflation of the concept of values (e.g. values are equated with choices). Such issues influence the validity and trustworthiness of the research (results, for example, may address preferences rather than values). Consequently, they also impact practice, because evidence from this research is used in the practice of value-centered approaches (Vanderford et al., 1992; Black, 2005; Pieterse et al., 2008; Plumb et al., 2009; Pollak, Childers, & Arnold, 2011).

Therefore, clarifying the concept of patients' values is an essential and fundamental step for further knowledge development.

To clarify the concept of values, this study adopted Rodgers' evolutionary model (Rodgers, 2000) for several reasons. First, the philosophical rationale that underlies this approach, in which concept analysis is based on inductive inquiry and on conventional standards, provides a foundation for further development of a concept through further research (Rodgers, 2000; Tofthagen & Fagerstrøm, 2010). Second, Rodgers' evolutionary model emphasizes that concepts change according to the time and the context. Rodgers distinguishes "entity views" in which a concept is described as some type of entity or 'thing' (e.g. words), from "dispositional views" which make use of concepts, defined as 'habits or capacities for certain behaviors' (p. 11). As such, a concept is the 'idea or characteristics' that are related to a word (p.85). Concepts equip me with two aims: using language effectively and practicing the concept mentally or physically. For example, when a researcher has a firm understanding of the concept of values, he or she can develop a ‘value-based approach’. In Rodgers’ view, a concept is dynamic, boundless, and influenced by time and context.

Rodgers’ evolutionary approach, which we adapt for use in this study, comprises the following six activities. They are not necessarily conducted in a linear process, but are normally undertaken simultaneously.

- Identify the concept with associated surrogate terms
- Identify and select appropriate setting and sample for data collection
- Collect the data (attributes, antecedents, references, surrogate terms, related terms, and consequences)
- Analyze the data
- Present an exemplar of the concept identified from the literature
- Identify the implications for further development of the concept (Rodgers, 2000)

Research Design and Methods

The literature across the disciplines of nursing, medicine, psychology, sociology, and theology employ the concept of values, in ways that help us to clarify it. As such, a systematic search was conducted via CINAHL, MEDLINE, PsycINFO, ATLA Religion Database, Social Sciences Citation Index, Philosophers Index with Full Text, Religion and Philosophy Collection, Books: Library Ebsco Discovery Service. Searching for *values*, along with other terms such as *preferences*, *wishes*, *attitudes*, and *beliefs* in the context of patients yielded millions of citations in English language publications. The large quantity of results was due to the use of the term *values* in the context of patients for three other major purposes: (1) as a verb to mean assessing and appraising something or someone (e.g. patients value experience); 2) as a basis for measurement (e.g. fasting blood value of 4 or less); 3) and, most commonly as a form of p values (the probability of something happening by chance). In order to limit the volume of citations, and ensure the concept of '*patients' values'* is reflected in the literature, we used the terms '*patient values*' OR '*patient preference**' (because these terms are often used interchangeably as surrogate terms).

The snowballing technique was also undertaken through a search of reference lists of the selected literature using backward forward tracking methods. This helped us to avoid overlooking relevant published and unpublished reports in the grey literature.

To be included in the review, references had to be: a) theoretical and empirical references containing data on patients' values (which may be understood as individual values, but in the context of disease), b) written in English, and c) published as full articles, books, or theses. No time period restrictions were applied through to May 2015. The references were excluded if: a) they lacked data on any of the elements of the concept of patients' values, or b) they focused mainly on values as belonging to one or more of the following: A health-care professional, or a profession, or an institution (or were referred to as health professionals' values, values of the profession, or institutional values).

A thematic approach was applied to analyze the data (Rodgers, 2000). References related to various disciplines were read and reread separately to identify words or sentences relevant to the attributes, antecedents, references, surrogate terms, related concepts, and consequences; these data were entered into a table, which was divided into sections for each discipline. Major themes related to the elements of the concept were identified through a repetitive iterative process of frequently organizing and reorganizing comparable patterns in the literature "until a cohesive, comprehensive, and relevant system of descriptors is generated" (Rodgers, 2000, p. 95). However, this process of reduction was not applicable to the surrogate terms and related concepts, which were simply recorded. As the purpose of the concept analysis is to identify both consensus and failure to define a concept across disciplines, this study considered not only the similar points in the literature, but also the disagreement; this is further explored in the discussion section. A practical exemplar was also identified from the literature that represented the characteristics of the concept of values. This method reduces researcher bias and enhances neutrality (Sandelowski, 1986)[4].

Results

The search yielded 914 citations. Snowball searching revealed an additional 88 references. All full references were screened based on the inclusion criteria. Of these121 books, theses, and articles that could explicate aspects of the key elements of the concept of values, were identified (Figure 2.1). The study also included the most commonly cited references; this provided a theoretical or conceptual foundation for the included studies across disciplines, such as works by Rokeach (1973) and Schwartz (2007). These 121 texts were classified by the disciplinary perspective in which each paper was grounded: medicine (46), nursing (28), psychology/sociology (34), ethics (5), philosophy (5), and theology (3).

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[4] See Appendix E for further methodological details.

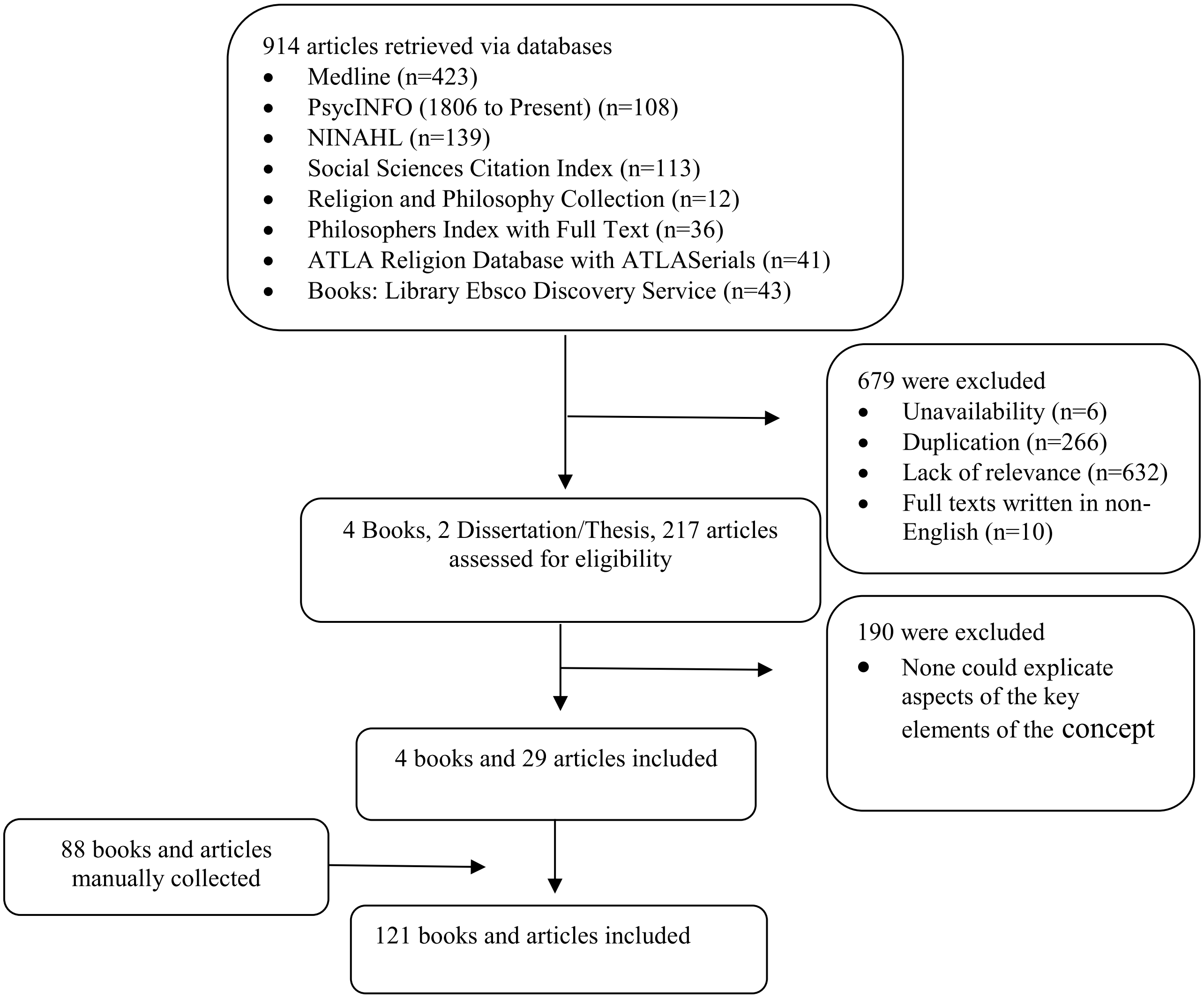

Figure 2.1

Flow Chart of Literature Selection Process

Following Rodgers (2000), we analyzed the concept of values not only on the basis of its intrinsic attributes, but also with attention to elements of its context (antecedents, references, surrogate, related terms, and consequences) (Figure 2.2). In addition, we define the concept, and provide an exemplar.

Attributes

According to Rodgers (2000), *attributes* are characteristics that allow for the definition of a concept in real-world terms (p. 91). We suggest six attributes of values that are categorized into two major groups: those pertaining to *the nature of values,* and those revealing *how values function*.

The Nature of Values

The first broad category of attributes is related to the fundamental features of values, focusing on what values are at their core. Four attributes are related to the nature of values: they are a form of belief, they are abstract, they are subjective, and they are uniquely significant to individuals.

Values as a Form of Belief

Many scholarly sources provide broad or ambiguous descriptors of the concept of values, using imprecise terms such as *features*, *things* (Menzel, Dolan, Richardson, & Olsen, 2002; Elit, Charles, & Gafni, 2010), *views* (Petrova, Dale, & Fulford, 2006), or *ideas* (Bowen et al., 2006). The reason for this imprecision may be that some researchers regard values as ‘self-evident’ and immutable (Quill, 1994). In the most recognized and quoted definitions, however, values are referred to as a type of *beliefs* (Rokeach, 1973, Schwartz, 2012) which are prescriptive or proscriptive (Rokeach, 1973, p. 6-7) – that is, such beliefs determine the desirability of an action and are centrally located within one’s belief system. By contrast, other types of beliefs within the system, which are more peripheral, are about facts or evaluation in terms of “goodness” or “badness” (p. 124).

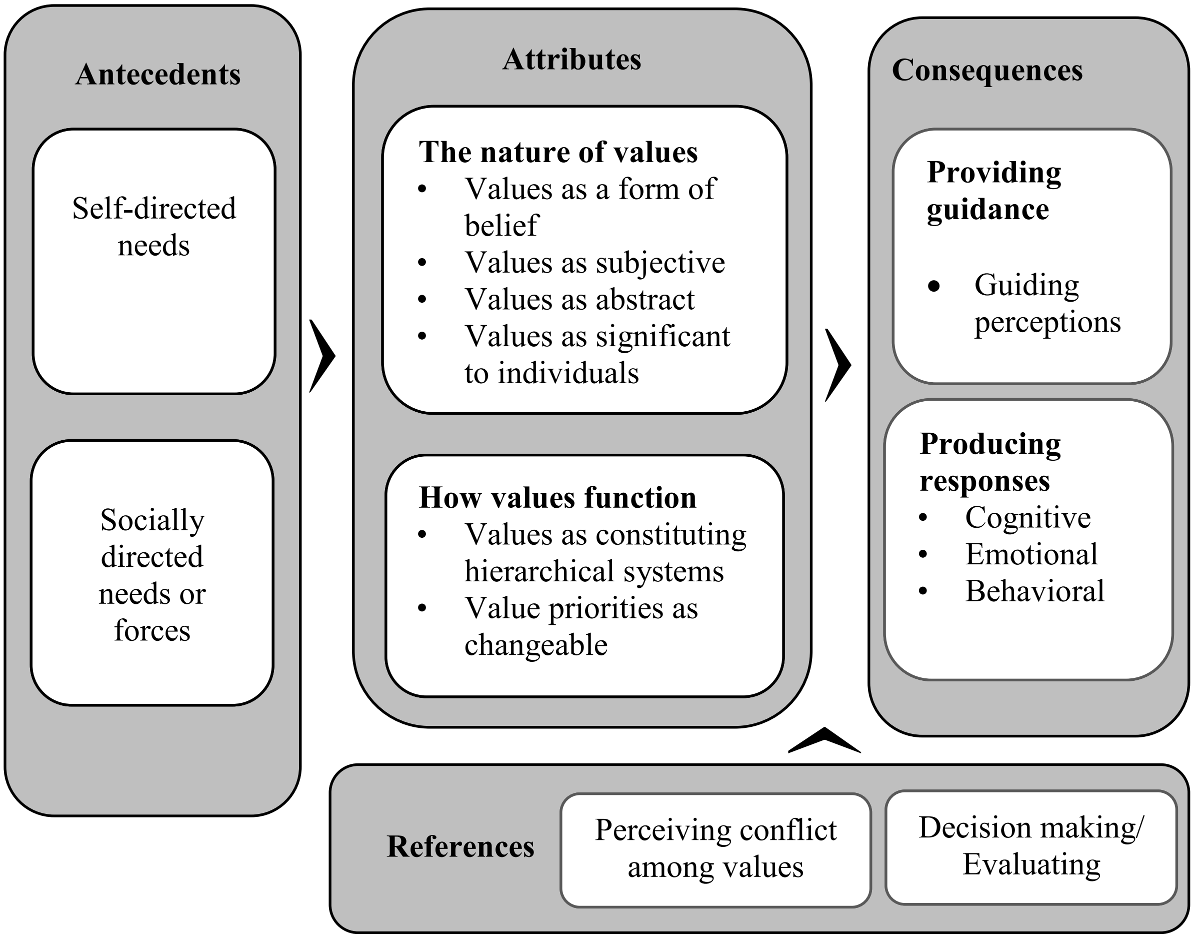

Figure 2.2

Theoretical Model of the Concept of Patients' Values

Values as Subjective

Individual values are frequently labelled as being subjective (Altamirano-Bustamante et al., 2013; Meadowcroft, 2008), defined as reflecting 'a personal point of view' (Wingfield & Badcott, 2007, p.7). Subjectivity is referred in the literature in a variety of ways – for example, values are described as *individual*, *personal* (Plumb, Stewart, Dahl, & Lundgren, 2009; Altamirano-Bustamante et al., 2013), *intrinsic* (Earley, Mentkowski, & Schafer, 1980), and *self-determined* (Huxtable, 2013), and said to be *freely chosen* (Plumb et al., 2009).The compelling reasons that values are subjective are that they are closely connected to the identification of the self (Lichtenberg, 1983; Petrova et al., 2006; Masters, 2009) uniquely acquired by each individual, and that they are established very early in life (Rokeach, 1968; Kalish & Collier, 1981). Such a set of subjective values in an individual may be held consciously or unconsciously (Farrell, 1987; Plumb et al., 2009; Lichtenberg, 1983). Values are not only subjective in nature, but may also be affective, given that they tend to be tied to feelings and emotions (Luce, 2005; Masters, 2009; Meissner, 1987; Segalla, 2006; Tung, Hunter & Wei, 2008).

Values as Abstract

The idea that values are abstract is expressed in several ways. First, a number of studies characterize *values* as not being concrete and not completely explicable through rationality (Valenti, Giacco, Katasakou, & Priebe, 2014; Thornton, 2006); they are seen as elusive (Elit et al., 2010; Charles & Gafni, 2014) and arguable (Wingfield & Badcott, 2007). Furthermore, the notion that values exist outside of concrete being means they have also come to be seen as decontextualized or ‘context-free.’ In other words, values such as joy, responsibility, health, justice, beauty, freedom, or obligation are not related to a specific situation or subject such as an intervention.

Another definition of abstractness in Merriam-Webster dictionary, is “difficult to understand”, also influences the ways in which values are viewed. Patients’ values are described as not being easily identifiable by others (Childress, 1970; Hug, 2000; Charles & Gafni, 2014), being rarely visible (Austgard, 2007) and there is a lack of suitable approaches to identifying them (Petrova et al., 2006; Altamirano-Bustamante et al., 2013; Peile, 2013). In addition, it has been noted that patients have difficulty expressing their values, given they may feel fear, shyness (Bosek & Savage, 2007; Curtis et al., 2001; Pieterse, Baas-Thijssen, Marijnen, & Stiggelbout, 2008; Loughlin, 2014), intimidation (Ubel & Loewenstein, 1997; Masters, 2009), or discomfort due to stigma in disclosing (e.g. values that are related to sexual orientation) (Curtis et al., 2001), and this may be overwhelming to some patients, in particular in critical situations (White et al., 2012). This difficulty is related not only to difficulty in expressing them but also to patients' lack of awareness of their own values (Childress, 1970; Lichtenberg, 1983; Farrell, 1987) and to the fact that a particular value may be meant and interpreted in a variety of ways by different people (Quill, 1994; Austgard, 2007).

Values as Especially Significant to Individuals

Personal significance is another attribute used frequently to describe the concept of values (Table 2.1). In some definitions, particularly in practical and concise ones, significance is the key element (Vanderford, Smith, & Harris, 1992; Fiset et al., 2000; O'Connor, Stacey & Légaré, p. 2006). The concept has been simply defined as 'what is most important to us' (Masters 2009, 395). Significance is also indicated using such terms as *worthwhile*, *highest regard* (Halpern, 1995; Fiset et al., 2000; Masters, 2009; Elit et al., 2010; Charles, 2014), *core* (Masters, 2009), *most dear* (Davidson, 1992), *meaningful* (Farrell, 1987), desirable (Meissner, 1987), and *fundamentally valuable* (Austguard, 2007; Darling et al., 2015). This attribute is usually described as being linked to the patients' perceptions of their lives and their world (Fiset et al., 2000; McCormack, 2003; Segalla, 2006) – for example, 'what is important in life and the kind of person one has to be' (Petrova et al., 2006, p. 708).

Table 2.1

Values as Especially Significant to Individuals

Examples of values as especially significant to individuals	Reference
"The features that matter most."	Lee, 2013, p. 1
"…what matters most."	O'Connor et al., 2006, p. 106
"To what they care about most deeply."	McCracken & Yang, 2006, p. 138
"Important agendas in daily life."	McCormack, 2003, p. 205
"What is most important to us."	Masters 2009, p. 395
"Core values are those values that are most important to us, the values that define who we are as human beings."	Masters, 2009, p. 172
"ideas about what is valuable, important, or right"	Darling et al., 2015, p. 8
"Values related to one's views about what is important in life and the kind of person one has to be."	Petrova et al., 2006, p. 708
"Processes of deciding whether something is good, worthwhile and important whether something is good, worthwhile and important."	Petrova et al., 2006, p. 708
"Values as those things that are held in highest regard or most important for that individual."	Elit et al., 2010, p. 279
"More important than anything else."	Murray-García, Selby, Schmittdiel, Grumbach, & Quesenberry, 2000
"Our judgement of what is valuable or important in life."	Wingfield & Badcott, 2007, p. 9
"What patients consider as important to decision-making."	Charles & Gafni, 2014, p. 205-6
"The term values refers broadly to those aspects of a healthy life that a person holds as most important—for instance, living an active life versus freedom from pain and suffering."	Halpern, 1995, p. 75
"What was most important to them."	Fiset et al., 2000, p. 131

How Values Function

In addition to the attributes that are related to the nature of values, two other attributes characterize the function of values. First, values constitute hierarchical systems; second, the priority of values is changeable in response to the context.

Values as constituting hierarchical systems

A *system* is defined as 'a whole with interrelated parts, in which the parts have a function and the system as a totality has a function' (Auger, 1976, p. 21). An individual's value system encompasses several values that are interconnected (some of these may be compatible, while some are in conflict) and positioned differently in a way that they configure a hierarchical order of values. This aspect of the concept of values has been the focus of theorists and empiricists in the disciplines of psychology, sociology, (Beckstrand, 1978; Daghfous, Petrof & Pons, 1999; Patterson & Blocher, 1989; Masters, 2009; Valenti et al., 2013), and nursing (Karimi & Clark, 2016).

In broader terms, the hierarchical-value notion was proposed initially in Pepper's (1941) discussion on selection and dominance of different values in different situations. This insight has continued to influence discussions of values through the decades. Twenty years later after Pepper, Kluckhohn and Strodtbeck (1961) directly proposed the 'rank-order of preference' to refer to the process of prioritizing values. In 1973, Rokeach defined *hierarchies* or *priorities* as "the ordering of values according to importance, in some sense" (p. 18). The most recent and widely used definition by Schwartz also places an emphasis on values that are organized and ordered based on their importance in a system (2012). In the empirical studies reviewed here, patients' values priorities were found to be influenced and prioritized differently based on the situation (e.g. disease) and the context (family, society) (Karimi & Clark, 2016; Lee, Low, & Ng, 2013).

Values as changeable?

Scholers have approached the question of whether and how values change in at least four markedly different ways. Values are variously viewed as 1) changing over time (Jensen &

Mooney, 1990; Kelly, 1991; Pollak et al., 2011; Elit et al., 2010; Chiong, 2013); 2) being relatively fixed (Petrova et al., 2006, Elit et al., 2010) and hard to change (Kalish & Collier 1981); 3) and being stable (Rokeach, 1973; Ridley, 1998; Nåden & Eriksson, 2004; Austgard, 2007). A fourth group posits basic values as being stable, but views ordered values as subject to change. The priority of values, and likewise the attributes of hierarchical systems that constitute it, is a reflection of the evolution of the concept of patients' values. Indeed, the notion of change in priority of values has emerged in the literature concurrently and in parallel with the notion of hierarchical values, as noted above. It is, indeed, viewed that the ranking of values may change or may be partly stable according to factors such as the patients' situations and their health capacities (Gensler, Spurgin & Swindal, 2004, p. 225). Change could also be due to new experiences, life circumstances, effective persuasion, societal values (Masters, 2009, p. 48), or biological processes such as normal aging (Mather & Carstensen, 2005).

Value stability, on the other hand, is a result of "experiencing satisfaction and is thus a result of the reinforcement of one's existing belief system" (Rokeach & Ball-Rokeach, 1989, p. 782). In the context of patients with particular chronic conditions, such as heart failure, diabetes, or cancer, patients may be limited in terms of their physical capability and they are also required to adjust their life-style and adapt a new one. These situations interfere with patients' usual values prioritization – for instance, the value of achievement may be important for a patient but the health situation will force him/her to change the priority of their important values (Karimi & Clark, 2016; Mahoney, 2000; Hodges, 2009).

Antecedents

Antecedents are the events and phenomena that inform and give rise to a concept (Rodgers, 2000). Scholars view the origins of values to be needs or forces (Singh & Rastogi, 2001; Schwartz, 2012; Vanderford et al., 1992), which can be classified in two major categories: self-directed needs and socially-directed needs or forces. Self-directed needs are related only to oneself, such as needs for control and mastery, variety, stimulation, and joy (Schwartz, 2012). Such needs are influenced by demographic factors such as age (Kalish & Collier, 1981), status in life cycle (Hewlett, Smith, & Kirwan, 2001), personality (Rokeach, 1973) and personal experience (Segalla, 2006; Sinding, 2006; Hirsch & Abernethy, 2012). Experience, for example, was noted to be an influential factor for patients who were diagnosed with heart failure and prioritized the value of pleasure by eating out. Experiencing worsening symptoms and hospitalizations due to nonadherence to low-sodium diet, however, could influence the patients' value priorities (health over pleasure) by prompting them to avoid eating high salt food at restaurants. These Self-directed needs are presented in the literature in different but parallel ways: as *authentic needs* (Capone & Stevens, 2013), *fundamental needs* (Meissner, 1987), *selfish needs*, (Rokeach, 2000) *individual needs* (Rokeach, 2000, p. 3), *internal forces* (Gaudiano, Nowlan, Brown, Epstein-Lubow, & Miller, 2013), and *biological organisms needs* (Meissner, 1987, Schwartz 2012, p. 4).

Socially-directed needs are those that tend to be social in nature. They are associated with the goals that come from families, groups, organizations, institutions, and society expectation, demands, forces, and cultures. The cultures of any of these social system levels have been identified as an important factor in influencing value development (Rokeach, 2000; Kelly, 1990; Patterson & Blocher, 1989, Hanssen, 2004; Petrova et al., 2006; Wingfield & Badcott, 2007). An individual's values, for example, can be shaped by their parents' values (Kalish & Collier, 1981). Given the major influence of social context, Hanssen (2004) argues that in order to study values, cultural values or contextual values ought to be assessed (Meissner, 1987). Whether they view religion as part of a culture or distinct from culture, a large number of researchers have found religiosity to be another major factor that influences values prioritization (Kuschel & Mieth, 2001). As such, in addition to the individual's needs, one's value prioritization may also be reinforced through culture/religion in a given social system.

References

References are the context or situations in which a concept occurs (Rodgers, 2000). In the context of health and illness, values are manifested in two main situations: 1) patients' values become involved in all decision-making activities, 2) patients' values also become active when there is conflict among those values, either within one's own value system or between these values and the values of other parties. In the context of health and illness, this may be manifested as conflict between patients' values and health professionals' values (Nåden & Eriksson, 2004), when an ill individual has to make a decision about therapeutic recommendations. Such conflicts are evident in the literature, in particular in the context of approaches to patient-centeredness in which patients have been encouraged to integrate and express their values in their own treatment decisions (Ubel & Loewenstein, 1997). The recognition of such conflicts is grounded in various approaches, such as motivational interviewing (Miller, 1983; Plumb et al., 2009), and decision aids (O'Connor, 1995, Ubel & Loewenstein, 1997), which require a variety of communication strategies, such as getting closer, informed flexibility, mutuality, transparency, negotiation, and sympathetic presence. In spite of the above, there are situations in which patients with cognitive problems (e.g. dementia), depending on their level of impairments, may not be able to make decisions in a way to pursue their values.

Related Concepts and Surrogate Terms

Related concepts are terms that have some association with a concept, but have different attributes (Rodgers, 2000). To that end, many authors used other terms in conjunction with the concept of patients' values that have different characteristics. These related terms are categorized into three groups: a) concepts that express a framework and a phenomenon related to values, b) concepts that are related to valuation, and c) other alternative concepts that are applied in connection to the concept of values. (Appendix H, Table H.1)

Surrogate terms, by contrast, are alternative terms with similar meanings (Rodgers, 2000) that may be used interchangeably with the term *values.* Surrogate terms may be investigated through the use of guiding questions. In the case of surrogates for values, we may ask: Are other terms applied for the same or a similar purpose as the concept of values? What are the multiple ways of expressing the concept of values (Rodgers, 2000)?

In this study it is notable, that some of the terms that identified as surrogate terms, including preferences, goals, interests, attitudes, and beliefs, are also used by researchers as related terms rather than surrogate terms; they are viewed as having different attributes and are distinguished from values. For instance, preferences are sometimes defined as a person's overall most-favored option (Llewellyn-Thomas & Crump, 2013), interests are defined by some scholars as being "dependent upon the values" (Kelly, 1990, p. 174), and goals are sometimes said to be influenced by values (Jensen & Mooney, 1990). In order to categorize these terms as either surrogate terms or related concepts, we first selected the six terms that were most commonly used in the literature as surrogate terms and related concepts, and then compared their attributes with the attributes of the concept of values (Table 2.2). *Core beliefs* and *life goals* were found to share a similar meaning with the concept of values and were thus identified as surrogate terms.

Attitudes, beliefs, preferences, and *spiritual beliefs* were identified as related terms. The term goals was the most difficult to categorize, so we have described it as a *potential* surrogate term.

Table 2.2

Analysis of Terms Used as Surrogate and Related Concepts

Term	Meaning Applied in the Literature	Analysis	Classification
Attitudes	A patient's *attitudes* focus on the desirability/undesirability of an option or outcomes (Llewellyn-Thomas & Crump, 2013)	*Attitudes* is inadequate as a surrogate term, given that it is concrete and evaluative in nature, and is associated with a specific object and situation (e.g. outcomes).	Related term
Beliefs	"Any simple proposition, conscious or unconscious, inferred from what a person says or does" (Rokeach, 1963, p.113)	*Beliefs* is inadequate as a surrogate term, as it refers to the simple convictions that a statement is true and is not abstract.	Related term
Core Beliefs	"Core beliefs are fundamental to a person's world view" and function as a powerful ego-defense, which is relatively resilient to change (Charles et al., 2006, p. 206; see also Sabatier, 1988 referenced in Charles et al., 2006).	*Core beliefs* have the same attributes as values, and may be used as a proxy measure for values.	Surrogate term
Spiritual Beliefs	*Spiritual beliefs* refer to a person's belief in a power apart from their own existence. (King, 1999, p. 292)	*Spiritual beliefs* are not core beliefs but are closely related to core beliefs and are connected to a specific domain of individuals' values.	Related term
Goals/ Life Goals	*Goals*, or personal aims, are important to a person, are small in number, and are likely to be most relevant to the choices that are related to treatment options (Fowler, 2011).	*Goal* is a potential surrogate terms because on one hand it may be related to a specific situation or object (e.g. an option), but on other hand it may be used as an abstract idea. However, the term	Potential surrogate term (goals) Surrogate terms (life

	"Life goals are objectives that a person strives to attain or avoid. They are hierarchically organized, accessible to conscious awareness and can be identified. Life goals may influence participation in a rehabilitation programme." (Nair, 2003, p. 200)	*life goals/ultimate goals* may be used as a proxy for values, as life goals are both abstract and important.	goal/ultimate goals)
Preferences	A *preference* is a person's overall most-favored option (Llewellyn-Thomas & Crump, 2013) based on patients' "perspectives, beliefs, expectations, and goals for their health and life." It is reached by "weighing the potential benefits, harms, costs, and burdens associated with different treatment" or disease management options. (MacLean et al., 2012, p. e1S)	*Preference* is inadequate as a surrogate term because the concept is related to an object and it is consequence of the process of evaluating and weighing options (e.g. treatment options) from different perspectives.	Related term

Consequences of Values

Consequences of values are the events that follow the manifestation, either consciously or unconsciously, of particular values. This review of the literature from different disciplines suggests that the consequences of values can be viewed as 1) providing guidance, as primary effects, or the ways values shape our perception; and 2) producing responses as secondary effects, or the ways values function.

Primary Effects: Providing Guidance

Values primarily provide guidance in the creation of standards to allow an individual to evaluate and judge others and oneself and also the treatment alternatives (Halpern, 1995; Austgard, 2007). Such effect is viewed as directive and organizational (Meissner, 1987). This fundamental mode of conduct has been regarded in a variety of ways in the literature, for example, as predominant reinforcers (Wilson & Dufrene, 2009), guidelines (Kalish & Collier, 1981), rules (Plumb et al., 2009), normative guidelines (Altamirano-Bustamante et al. 2013), criteria (Childress, 1970; Kalish & Collier, 1981; O'Connor et al., 2006), an approval-disapproval continuum (Kluckhohn, 1951, p. 395), directions (Wilson & Murrell, 2004), means (Kluckhohn, 1951; Kinnane & Suziedelis, 1966; Beckstrand, 1978; Patterson & Blocher, 1989; Quill, 1994), implicit or explicit standards (Quill, 1994; Jensen & Mooney, 1990; Raz, Korsgaard, Pippin, Williams, & Wallace, 2003), and value judgments (Beckstrand, 1978; Lichtenberg, 1983; Halpern, 1995; Nicoll, Reed, & Shearer, 2004). They have also been related to the concept of the superego (or individual's evaluative judgments) (Lichtenberg, 1983). Secondary effects, however, as another aspect of consequences are more functional.

Secondary Effects: Producing Responses

While guidance is a fundamental aspect of the consequence of values, producing responses are the secondary effects of values. These consequences are multifaceted, affecting cognitive, behavioral, and emotional responses.

Cognitive impacts

It is found in the literature that the cognitive impact of values can be categorized into four functions. The first is intellectual production, which is the influence of values on creating attitudes, perspectives (political, religious), and decisions. Patients’ values influence choices and preferences about choices (Kinnane & Suziedelis, 1966). Decisions are made based on the extent to which a treatment is consistent with patients' values (Kissane et al., 2010) and whether patients’ prioritized values are pursued. The second cognitive impact of values of values may be self- justification, which is engaged in order to rationalise our thoughts, decisions, and actions. Such impact is also described in discussions around self-deception and ego-defensiveness (Rokeach, 1973). The third cognitive impact can be perceived as self-identification (Ridley, 1998; Huxtable, 2013), in terms of who we are and what we value the most. The fourth impact, which is patient empowerment (Kvåle & Bondevik, 2008), has been examined in terms of the consequences of the patient-centered care plan, in which patients’ values are explicitly integrated in the plan of nursing care.

Behavioral impacts

Individuals’ values can contribute to behavior, either positively or negatively; in other words, values may have enhancing or destructive effects (Shriver, 1980) on individual preferences, decisions, and behavior (Bowen et al., 2006; Petrova et al., 2006; Llewellyn-Thomas & Crump, 2013). In the caring context, patients’ values have been the focus in order to understand adherent or non-adherent behavior and to take steps to support patients according to their values (Ahola, 2015; Karimi & Clark, 2016). However, the positive or harmful impact of values on behavior depends on patients' prioritized values and the impacts of these values on their subsequent behavior (Petrova et al., 2006; Llewellyn-Thomas & Crump, 2013). Nonadherent behavior, for example, arises from situations where there is 'conflict', 'clash', or 'inconsistency' (Ahola, 2015; Valenti et al., 2014) between a patient's prioritized values and healthcare recommendations. Such a situation is described as 'a complex and often situationally dependent process' (Beckstrand, 1978; Karimi & Clark, 2016).

Emotional impacts

Emotional feelings and psychological health status can result either from success or failure in pursuit of values (Plumb et al., 2009). These results may impact patients' feelings – either positively causing satisfaction, or negatively causing guilt, shame, stress, and anxiety (Luce, 2005; Meissne, 1987; Segalla, 2006; Tung, Hunter & Wei, 2008).

Definition of Values

The conceptual definition of the concept of values that is proposed in this concept analysis is based on attributes. As such, values are defined as core beliefs, which are abstract and subjective in nature and perceived as very significant to individuals; they function within a system and a priority of values can be changed under certain circumstances.

Exemplar

A real-life example retrieved from a case study (Stawnychy, Creber, & Riegel, 2014) is presented in table 2.3 to further clarify the critical attributes and consequences of the concept in practice.

Table 2.3

Exemplar

A patient with Class IV heart failure (HF), is described as a non-collaborative partner, was re-hospitalized because of shortness of breath and worsening symptoms. She had been hospitalized nine times in the previous year as a result of nonadherence to medication, low sodium diet, and missing follow-up appointments. During motivational interviewing, she explained that "she felt overwhelmed and fatalistic" (Stawnychy et al., 2014, p. 3), because she was pressured to follow health professionals' recommendations and was provided no alternatives (which hampered a key personal value of self-directed action). Her emotional reaction and frustration intensified due to negative treatment by nursing staff as a result of her frequent readmissions. Staffs labeled her as a "frequent flyer" and "noncompliant", and said "You are back once more?" (p. 4).

In this case, the reference or situation for the occurrence of the concept of values is health-related decision-making in the context of HF. Three patient's values – self-directed action, respect, and good health– were involved. These values reflect certain attributes: they were abstract beliefs (as they existed in thought, became identifiable through the use of a suitable approach that encourages her to disclose her perceptions), they were subjective, and they were significant to her (as she made her decisions based on them). Further attributes of values, including constituting a cognitive system and changeability of the priority of values, were also exemplified. The patient came to the hospital to receive care (to pursue the value of being healthy), but she experienced a paternalistic model (which inhibited the pursuit of self-direction) and perceived that she was not respected due to her frequent rehospitalisation.

Consequently, in this situation the values of respect in addition to self-direction became more prominent cognitively, in which the value of respect was prioritized over the value of being healthy; this reflects a change in priority of values. The consequences were emotional (feeling overwhelmed) and behavioral responses (including nonadherence and missing scheduled appointment).

Discussion

This study employed Rodgers' evolutionary approach using literature in various disciplines. The analysis of the literature revealed that the evolution of the use of the concept of values has expanded significantly over the last half century. It has been applied to elucidate a variety of behaviors in different contexts, such as the therapeutic relationships between patients and healthcare professionals, patients' roles in medical decisions, patients' autonomy, and patient-centered care. During this time, there has also been a major evolutionary shift in the concept of values, in particular within the disciplines of sociology and psychology. Researchers have defined the concept of values, proposing an underlying structure, differentiating values from other concepts such as attitudes and beliefs as follows: attitudes are evaluative associations and directed toward an object (people, behaviors, events, places) and the situation in which the object is established (e.g. positive opinion of a patient with HF about eating out with friends at a restaurant on Christmas Day). Beliefs in general are the convictions that a statement is true (e.g. self-care improves HF patients' wellbeing) (Daghfous et al., 1999, Kamakura & Novak, 1992; Rokeach, 1973).

We, however, found the task of clarifying the concept of patients' values to be particularly challenging for three reasons. 1) The concept of patients' values employed in the studies is grounded mainly in sociology, which conceptualizes individual values in the context of social phenomena (such as voting and behavior of consumers) (Daghfous et al., 1999). Chronic disease, however, has a comprehensive impact on patients' lifestyle; it therefore influences the references related to the concept, which has a significant impact on other elements, such as attributes and functions. 2) Authors express disagreement over the nature and attributes of values; this may reflect different fundamental assumptions based on different theoretical frameworks. They also disagree about whether can be measured; this makes it difficult to identify their attributes precisely. 3) Studies in the fields of nursing and medicine reveal that those who apply values-based approaches to care may be inconsistent in focusing on patients' values and may use other concepts such as preferences interchangeably with values. The attributes of those other concepts may distort our perceptions on values.

The following discussion considers each of those challenges in turn.

The comprehensive influence of chronic disease. We argue that different disciplinary perspectives may create a challenge for the analysis of the concept of values in the context of health and illness. Sociological perspectives on values view human behavior in relation to surrounding cultural and social structures. This differs from the health-related disciplines. In these fields patients' decisions is mainly viewed as self-directed and have personal health-status implications. Adherence/nonadherence, compliance/noncompliance, autonomy, euthanasia in the context of chronic disease or end-stage organ failure are examples of such self-directed decisions or behavior. Some health contexts, moreover, are neither self-directed nor sociological. In the context of dementia, – a situation in which a person' cognitive condition declines– not only the reference but also the attributes of the concept of patients' values differ. However, in order to understand the impact of condition, researchers must examine whether or not and to what extent the patients' values change during the dementia process. Dealing with this ambiguity is crucial, as this knowledge may enhance our understanding of patients' values in the future. These findings may also equip us to use the concept in supporting patients with dementia in their decision making (Carpenito-Moyet, 2010). The context of physical disease also influences the attributes and functions of individuals' values (Karimi & Clark, 2016). Understanding this influence will require more research focusing on patients' values– a field that researchers have emphasized and recommended for further research since the 1950s (Meehl, 1959; Krasner, 1965).

Differing theoretical assumptions. The findings of this evolutionary concept analysis were based on points of consensus within the literature. Nonetheless, according to Rodgers (2000) instances of disagreements must be elaborated as outliers (Rodgers, 2000) in the concept analysis because the study of incongruities, another aspect of concept analysis research, can also generate significant insights. One of the important disagreements in the literature is about measuring values as they are seen through the following lenses: a) values are measurable, b) values are difficult to be measured, c) some of the values are measurable and some are difficult to be measured. Indeed, while different approaches (e.g. the standard gamble, time trade-off, or visual analog scale) have been developed and used to measure patients' values (Llewellyn-Thomas et al., 1981; Woloshin et al., 2001), some of the authors argue that the notion of value measurement is ideological /philosophical rather than psychological (Ehrlich & Wiener, 1961; Childress, 1970; Charles & Gafni, 2014; Kissane et al., 2010).

In closely examining these refuting views on the measurement of values, it was noticed that they are basically anchored in three distinct presumptions which were based upon various delineations for values and measurement. First, in the above approaches such as, standard gamble and time trade-off that tend to measure patients' values (Llewellyn-Thomas et al., 1981; Woloshin et al., 2001), the focus is on the relative values that individuals express for a consequence that they may face. These approaches intend to assess an individual's evaluation and preferences for, for example, treatment options that do not conform to the individual's values. Second, as in the Rokeach Value Survey (Rokeach, 1973), a widely used and valid value-measurement instrument, measurement means determining the order for values in terms of their importance. In other words, measurements in use of this approach indicates 'relative ranking' of an individual's values. Third, measurement simply referred to collection or determination of patient' values. As such, the major reason for this disagreement concerning value measurement is a conceptual inconsistency. Perhaps identifying and ranking values demand a clearer and more precise term than simply 'measuring'. Moreover, measurement in general has been viewed as problematic and complex (Charles & Gafni, 2014; Entwistle & Watt. 2006; Kissane et al., 2010) because patients may not tend to express their values or may feel they may be left isolated without their physician' support (Entwistle & Watt. 2006).

Imprecise use of the concept of values. Likewise, the incongruence in values-based approaches between the concept of patients' values as a center of their focus, and the way that the approach mirrors the process of achieving this goal (Kelly, Heath, Howick, & Greenhalgh, 2015) was another challenge in examining concept of patient's values. This was evident in approaches, such as patient/person-centered care (Vanderford et al., 1992; McCracken & Yang, 2006; Hirsch & Abernethy, 2012), elicitation of patient values (Black, 2005; Pieterse et al., 2008), clarification of values (Masters, 2009; Charles & Gafni, 2014), and motivational interviewing techniques (Plumb et al., 2009; Pollak, Childers, & Arnold, 2011). Indeed, these processes are grounded on patients' preferences and selections among a range of alternative therapeutic options. Although patients' preferences, choices, or selections might be a reflection of patients' values, they differ from values in a variety of ways. For those patient-centered approaches that are value-based, it is expected that those prioritized patients' values are identified and then the evidence, solutions, decisions, and care plans are accordingly developed, set up, or individualized to support the patients' values in their decisions. However, in spite of acknowledging and emphasizing the importance of values in those approaches, the directions of the researchers' attempts nonetheless deviated from their intentions. This value confusion at the heart of the treatment was a challenge and concern in this study. Such deviance raises questions around exactly what drives such a shift. Why is the complex concept of values generally and naively seen as a self-evident concept, while much focus has instead been spent on the related concepts? Attention must focus on how this view can be amended and replaced by a proper definition in research, approaches, models, theories, and practice.

The findings of this analysis have implications for further development in nursing diagnosis, a research area in which key concepts must continue to be defined. Most of the nursing diagnosis promoting interventions includes values clarification and value elicitation to achieve effective outcomes. These outcomes improved by such value clarification, including promoting physical activity, copying, rest and sleep, nutrition, health status, relationships, sexual activity, self-perception, or safety/protection. However, values are not clearly defined and often used in undefined and underlying conjunction with the concepts of beliefs and life goals. As such, integration of values clarification in the nursing care plan remains a challenge for the majority of nursing diagnoses.

Limitations

Although the applied strategy in this study served to capture potentially relevant papers in relation to patients' values, this may have resulted in missed data. This study was limited to literature in English and mostly covered the Western understanding, which may limit cross cultural analysis. We propose that for such fundamental and ancient concepts such as values, it is crucial not only to carry out research across disciplines and over time, but also to draw on both Western and non-western sources, which includes non-English sources. Such broad sources may contribute to the profound knowledge development and expand the concept of values in the discipline of nursing. The sample selection of this study also did not cover print media, which could have been an important data source for this concept. The included studies also lack information concerning the concept of patients' values in practice. Conducting interviews with patients and nurses could have provided important data on patients' values. These limitations also deliver scopes for future conceptual thinking and research.

Conclusion

Rodgers' evolutionary approach (Rodgers, 2000) allows for a cross-disciplinary comparison that permitted us to enhance our understanding of and to clarify the concept of values. Patients' values are a paramount and fundamental concept, which is distinct from other concepts such as attitudes, preferences, choices, needs, and beliefs. Accordingly, it is essential to define the term for use in models, theories, and nursing care plans. The lack of such clarification in the literature creates a significant challenge for the reader or learner hoping to understand those approaches that are value-based. In the absence of this clarification, values may be viewed as a self-evident concept, creating further ambiguity around the idea. The significance of such understanding is crucial, as a broad spectrum of decisions – the most important consequences of the concept of values – are made in the context of self-care (e.g. adherence, nonadherence, and participating in learning opportunity) on a daily basis, in particular by patients with chronic disease. Clarification of the concept, thus, can guide nursing practice and patient care pragmatically (Duncan et al. 2007). Such analysis also may provide a potential foundation for conducting research to develop more effective nursing care plans, assessments and interventions to support patients in their health-related decisions.

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Chapter 3: How Do Patients' Values Influence Heart Failure Self-Care Decision-Making?: A Mixed-Methods Systematic Review[5]

Abstract

Background

Values are central to ethical and effective nursing and health care. However, in relation to heart failure the role that patients' values have in influencing self-care is poorly understood.

Methods

A mixed-methods systematic review was conducted using a critical meta-narrative synthesis approach to synthesizing qualitative and qualitized data. Nine databases were searched (14 March 2014). To be included in the review, studies had to contain data on heart failure patients' values and self-care behaviors, include adults aged ≥18 years with symptomatic heart failure, and be published ≥2000 as full articles or theses. Study quality was assessed using a mixed-methods appraisal tool.

Findings

Of 6467 citations identified, 54 studies were included (30 qualitative, 8 mixed methods, and 16 quantitative; 6045 patients, 38 lay caregivers, and 96 health care professionals). The synthesis identified multiple bi-directional interactions between heart failure, patients' values, and self-care. Patients are motivated by self-related and other-related values. Self-related values are tied directly to intimate personal feelings (self-direction, pleasure, and being healthy) or related to individuals' life circumstances (maintaining a healthy lifestyle and financial balance). Other-

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[5] This study was published in the *International Journal of Nursing Studies* and was formatted according to the style required by the journal.
Karimi, M., & Clark, A. M. (2016). How do patients' values influence heart failure self-care decision-making?: A mixed-methods systematic review. *International Journal of Nursing Studies, 59*, 89-104.

related values, which are fundamentally socially-based, are related to benefits received from society (social recognition and socialization) and social obligations (responsibility, observing traditions, and obedience). For each decision, several values are involved; some are incompatible and some are in conflict. Patients make their self-care decision based on the values they prioritize and those that are blocked.

Conclusion

Values are integral to how patients approach and undertake HF self-care. These values both affect and respond to this self-care and the severity of HF symptoms. Values extend to those relating to the self and others and incorporate a range of personal, life, and social dimensions. Values are not fixed, normative or similar to those held by nurses and other health professionals. Future interventions to improve HF self-care must address and respond to the complexity of patients' values and how they influence patient behavior in undertaking heart failure self-care.

Keywords

- Decision-making;
- Heart failure;
- Mixed-methods;
- Patient-centered care;
- Self-care;
- Values

What is already known about the topic?

• Patient values are important to understand and respond to in nursing care for ethical and practical reasons.

- Heart failure is a very common and burdensome syndrome with high costs in high income countries; heart failure self-care involves a wide range of complex behaviors.
- Understanding and incorporating patient values into healthcare is important to promote effective heart failure self-care.

What this paper adds

- The process in which patient values influenced HF self-care was fluid and iterative, incorporating values that were prioritized and/or blocked.
- A wide range of values associated with the self and others influenced HF self-care.
- The effects of HF on self-care were cyclical and iterative – self-care and its behaviors influenced which values the patients prioritized while values also influenced HF self-care behaviors.

1. **Background**

Whether and how health professionals incorporate patients' values into care are important ethical and practical issues. Values are defined here as being abstract core beliefs which start to develop in a person's early years but then guide and are expressed in behaviors over a lifetime (Rokeach, 2000 and Schwartz, 2006). As such, values exist and guide decisions across many domains of life, including social, family, political, sexual, and religious realms (Caprara et al., 2006, Honeycutt and Milliken, 2012; Padilla-Walker et al., 2012). Values are diverse and can also evolve markedly over time, for example, key aspects of human life such as health, love, helpfulness, honesty (Rokeach, 2000 and Schwartz, 2006), can be influenced by particular circumstances, such as age or single 'major' events (Schwartz, 2006).

Incorporating patients' values into care is central to nursing because it is ethical to do so (The Canadian Nurses Association, 2008). This recognizes patient autonomy in decision-making when choosing an alternative from a number of care options and avoids paternalism on behalf of the nurse (Noone, 2002). Patients' values should be incorporated into nursing care decisions because these personal values influence patients' behaviors (Feather, 1995 and Torelli and Kaikati, 2009). A range of nursing theories and models can help practicing nurses integrate patients' values into their care, for example: via patient-centered theory (Abdellah et al., 1961), the Oberle and Raffin Model (Oberle and Bouchal, 2009), or the brief motivational interviewing approach (Miller, 1983). These approaches involve exploring and responding to patients' values to improve positive patient outcomes, such as adherence, and patient satisfaction (Constand et al., 2014 and O'Connor et al., 1999).

Heart failure (HF) is a common condition affecting up to 10% of adults aged over 65 years in high income countries but HF outcomes, avoidable hospitalizations and symptoms, can be improved by effective HF self-care (Clark et al., 2014 and Riegel et al., 2009). This self-care involves consuming medications as prescribed, seeking help promptly from health professionals to manage symptoms, restricting salt and alcohol consumption, doing regular physical activity, checking weight and fluid intake, and monitoring mental health (Mahoney, 2000, Scotto, 2003, Sethares et al., 2014 and van der Wal et al., 2010). The effects of this self-care are important because HF is widely prevalent across high income countries (due to rapidly aging populations) and symptoms are burdensome on patients, their families (Clark et al., 2008), society, and healthcare systems (Robertson et al., 2012 and Zannad et al., 2009). For example, worsening HF severely reduces quality of life (Goodman et al., 2013), results in frequent rehospitalization, and high health care costs (Robertson et al., 2012 and Zannad et al., 2009). With the aging global population and greater survival from myocardial infarction, this burden is increasing and will continue to rise (Ambrosy et al., 2014 and Bleumink et al., 2004).

1.1. Values and heart failure self-care

Nurses and other health professionals have an important role in promoting effective HF self-care. Patient values are a particularly important facet of HF self-care because they stand to influence HF self-care behaviors – which themselves influence quality and length of life (Moser et al., 2012 and Poelzl et al., 2014). While attempts have been made to understand which factors influence and improve HF self-care behaviors (Jaarsma, 2005, Siabani et al., 2013 and Wu et al., 2008), poor self-care remains dominant worldwide (Ambrosy et al., 2014). Less than half of HF patients exercise regularly (Nieuwenhuis et al., 2012), less than 40% of patients adhere to prescribed medication regimens (Nieuwenhuis et al., 2012 and Riegel et al., 2011) or monitor weight daily, while as few as 10% consume a low-sodium diet (Lainscak et al., 2007 and Ni et al., 1999). Interventions to support effective HF self-care have inconsistent effects (Chaudhry et al., 2010, Clark and Thompson, 2008 and Savard et al., 2011) and the relationships amongst knowledge, self-care practices and outcomes is unclear (Davis et al., 2012).

Given that HF self-care is primarily based on patient decision-making in the home, outside of the direct control and influence of health professionals, and values are practically and ethically central to concepts of health and nursing care, a pivotal but neglected element relates to whether and how patients' values influence HF self-care (Clark et al., 2014, Cortis and Williams, 2007 and Hicks and Holm, 2003). This synthesis is the first to bring together research findings regarding the influence of patients' values on HF self-care. This knowledge can be used to help researchers and health-care professionals better understand self-care in patients with HF.

2. Methods

Patients' values can be inferred from qualitative or quantitative data. For example, qualitative studies can address what is important to patients from their own perspectives ("Should I remove salt from my diet?") while quantitative studies may study the roles of factors in patients' decision-making processes. Accordingly, this systematic review (SR) synthesizes the full range of qualitative, quantitative, and mixed-methods data. Using different types of data in this way generates more comprehensive (Creswell and Plano Clark, 2011), "interdependent" (Strauss and Corbin, 1990, p.32; Tashakkori and Teddlie, 2010, p. 432), and interrelated (Fielding and Fielding, 1986) findings.

In order to synthesize the qualitative and quantitative research, we used a modified form of critical interpretive synthesis (CIS) applied to synthesizing qualitative and quantitative research (Dixon-Woods et al., 2006). This modified approach is called: critical meta-narrative synthesis (CMNS). In contrast to the CIS approach, in which key concepts are extracted from the findings of qualitative studies and discussion sections of quantitative studies, the CMNS approach uses different kinds of data, including qualitative and quantitative studies to discover what is beyond ("meta") the narratives. Importantly, narrative, which is also called minimal story, constitutes meaningful relations between events that might be metaphorical, metonymical, or thematic (Herman and Vervaeck, 2005).

The CMNS approach allows for quantitative data to be transformed into qualitative data (or "qualitized") through systematic profiles (Tashakkori and Teddlie, 1998), and critical questions (Smith & Osborn, 2007) that are asked to further extract narratives from the data. Although meta-ethnography has traditionally put emphasis only on narratives drawn from qualitative research, quantitative data have qualitative aspects that can be extracted through the process of transforming quantitative data into narrative data (Tashakkori and Teddlie, 1998). We applied four types of profiles (Table 3.1) to transform the extracted quantitative data that had the potential to be 'qualitized', or converted into narratives.

Table 3.1

Generating Narratives from Quantitative Data.

Systematic profiles			**Critical questions***
Technique	Focus	Example	
Modal profile	The most frequently occurring attributes	If the majority of HF were 70- to 80-year-old group, they were described as elderly individuals	• What is this study trying to say about patients' values? • Are patients' values explicitly identified? If so, what are they? • How do participants' answers to the questions enable me to gain a sense about patients' values and their influence on self-care decision-making? • Do patients' values facilitate, hinder, or nullify self-care adherence? • Are there other individual or contextual factors (such as age, gender, severity of HF) that influence patients' values and self-care decision-making? And how? • How different (or similar) are patients, family care givers, and health professionals' perspectives about the influence of patients' values in self-care decision-making?
Average profile	Average of the particular variables	A finding of "mean HF knowledge scores were 14 (adequate knowledge score is defined >10)" was qualitized as meaning that generally, HF patients had adequate HF knowledge.	
Comparative profile	A comparison of key outcomes	A finding of "the traditional remedy belief score was significantly higher among patients who had a positive family history of HF ($P < 0.001$)" was qualitized as follows: patients with a family history of HF believe in traditional remedies.	
Holistic profile	A combination of the modal, average, and comparative profiles	A finding of "there was a negative correlation between relogicity and treatment adherence ($r = -0.\ 15$, $p = 0.041$ in patients 60-80 years" was qualitized as follows: elderly patients' religious beliefs relate to treatment non-adherence.	

*Adapted from interpretive phenomenological approach (Smith & Osborn, 2007)

While some of the constructed narratives were interpretive in nature (in particular, those derived via the holistic profile), further efforts were made to optimize the interpretation of quantitative data. For example, frequently reading and reflecting on the findings and identifying answers to the critical questions (Table 3.1), provided an understanding of the phenomena in greater depth (Johnson and Christensen, 2012) and facilitated the investigation of relationships between findings from two types of data.

Hence, through the process of reading and re-reading the studies, the key metaphors, phrases, ideas, and/or concepts and the relationships between them were identified. The interpretations of one study were translated into the interpretations of another (Noblit and Hare, 1988) through three strategies: (a) reciprocal translation (studies that are about similar things), (b) refutational synthesis (studies that refute each other) such as the results of a study on spirituality, and (c) lines-of-argument synthesis (studies that suggest a line-of-argument). Patients' customs, religious and spiritual beliefs influenced self-care decisions in different ways (Black et al., 2006 and Kaholokula et al., 2008). The line of argument (or hidden meaning) that emerged in this example was the role of tradition. Thus, values were understood to contribute to adherence or nonadherence depending on patients' spiritual beliefs and on the hierarchical structure of their values.

2.1. **Study selection**

The term 'value' was defined throughout the synthesis as abstract, core beliefs, which develop early and guide an individual's behavioral practice (Rokeach, 2000 and Schwartz, 2006). To be included in the review, studies had to contain data on patients, family caregivers, or health professionals' perspectives in relation to HF patients' values and self-care behaviors. In addition, studies had to include adults aged ≥18 years with symptomatic HF (New York Heart Association [NYHA] classes II–IV), be published in English in journals during or after 2000 as full articles or theses, and to have applied qualitative, quantitative, or mixed (qualitative and quantitative) methods. Abstracts and reviews were excluded, as were studies containing data from patients with HF who had physical disabilities or mental health problems, such as cognitive impairment or depression, because these factors impact patient beliefs (Korn et al., 2014). Studies undertaken before 2000 were excluded due to differences in care of patients with HF likely to occur before this date.

2.2. **Search strategy**

The systematic search was designed by a health sciences librarian and conducted on March 14, 2014 in the following databases: MEDLINE In-Process and Other Non-Indexed Citations, Ovid MEDLINE 1946-, Ovid Embase 1996-, Ovid PsycINFO 1987-, EBSCOhost CINAHL, SocINDEX, CSA Sociological Abstracts, Web of Science: Science Citation Index and Social Sciences Citation Index, and Scopus. The search included terms related to three concepts: self-care, values, and HF. Appropriate database-specific subject headings and keywords were used to retrieve literature about each of these concepts. In relation to patients' values, the search also used: values, beliefs, attitudes, perceptions, choices, preferences, and motivations. This allowed exploration of articles or theses that explicitly or implicitly related to patients' values and HF self-care behaviors.

Study quality was assessed using a mixed-methods appraisal tool (MMAT)[6] (Pluye et al., 2011), a valid and reliable tool for the assessment of the methodological quality of quantitative, qualitative and mixed-methods studies (Pace et al., 2012). Studies were ranked as being of low, moderate or high quality. Those with a low ranking were excluded because of the potential for results to be misleading (Dixon-Woods et al., 2007 and Moher et al., 1998). Furthermore, in order to reduce the potential for bias in this systematic review, we used systematic search strategies[7] and selective inclusion and exclusion criteria. Any negative or refutational findings were included in the synthesis; each step in the synthesis was conducted by two independent

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[6] See Appendix I
[7] See Appendix M

reviewers. Frequent meetings were held to discuss and resolve disagreements and clarify uncertainty[8].

During the CMNS approach, HF patients' values were identified and labeled based on the definitions of values in two common theories of basic values, those of Rokeach (1973) and Schwartz et al. (2012). The theory of values and belief systems by Milton Rokeach (1973) has been extensively adopted and has influenced the study of human values in a wide range of disciplines and contexts. Building upon Rockeach's model (1973), Schwartz et al. (2012), Schwartz (2006) expanded the conceptual discussion of values and their structure in order to extract more applicable, specific results. Schwartz and Rokeach's conceptualizations and classifications of an individual's values were employed to capture patients' values from narratives drawn from qualitative or qualitized data.

3. Results

The search identified 6467 studies. These were initially screened via title and abstract review, resulting in the full-text review of 579 papers (Fig 3.1). Of these, 54 met the criteria for inclusion[9] . Of these 54 studies, only 5 explicitly discussed HF patients' "values" in relation to self-care behavior (Clark et al., 2009, Cortis and Williams, 2007, Hicks and Holm, 2003, Hodges, 2009 and Scotto, 2003). However, the remaining studies contained implicit data both in the form of other terminology (see above) or as information embedded in explanations of behavior.

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[8] See Appendix K for further details about methodology.

[9] Three studies were excluded due to low quality

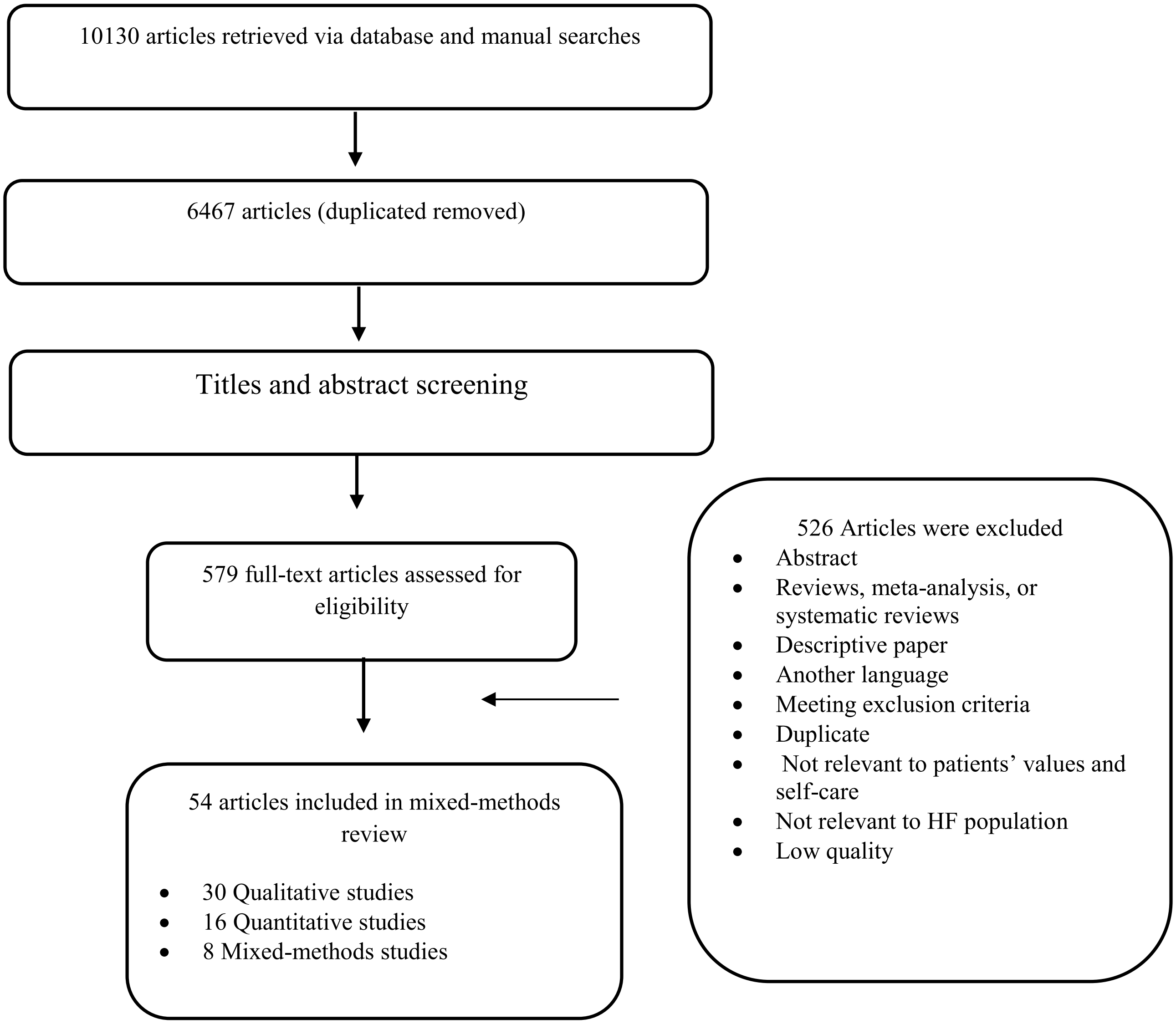

Figure 3.1

Flow Chart of Literature Search.

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Table 3.2

Description of Studies Included in the Mixed- Methods Systematic Review

First author/ year	Primary Focus	Methods	Country	Data collection method	Sampling	Participants	NYHA Class	Mean age	Scoring MMAT
Ågård, 2004	Pt' knowledge of and attitudes toward medical information	QUAL (GT)	Sweden	SSI	Convenience	Pt (40): M (25), F (15)	II (13), III (26), IV (1)	75	M
Artinian, 2002	SC behaviors	QUANT (Descriptive correlational)	USA	QUEST	Convenience	Pt (110): M (86), F (24)	NR	64	M
Barnes, 2006	Views of the family Cg of older HF Pt	MM	UK	QUEST & SSI & FG	Convenience	Pt (542): Cg (213 HCP (79)	I /II (329) III/IV (213)	NR	M
Bennett, 2000	SC strategies for symptoms management	QUAL (Descriptive)	USA	FG	Convenience	Pt (23): M (16), F (7), Cg (18)	NR	60	M
Bennett, 2005	Medication and dietary compliance beliefs	QUANT (Descriptive)	USA	QUEST	Convenience	Pt (306): M (185), F(131)	I (21), II (58), III (80), IV (43)	64	M
Bentley, 2005	Factors related to non-adherence to LSD	QUAL (Descriptive)	USA	SSI	Convenience	Pt (20): M(12), F (8)	I (2), II (7), III (11)	60.2	M
Black, 2006	Spirituality and compliance	QUANT (Correlational)	USA	QUEST	Convenience	Pt (95): M (60), F (35)	NR	72	M

Table 3.2 (*continued*)

First author/ year	Primary Focus	Methods	Country	Data collection method	Sampling	Participants	NYHA Class	Mean age	Scoring MMAT
Boren, 2001	HF women's experiences	QUAL (GT)	USA	SSI	Theoretical	F (15)	I (1), II (8), III (5), IV (1)	NR	M
Bosworth, 2004	Pt' descriptions of components of quality of life	QUAL (GT)	USA	FG	Convenience	M (15)	I/II (10) III/IV (5)	NR	M
Cholowski, 2007	Predictors of medication compliance	QUANT (Correlational)	Australia	QUEST	Convenience	Pt (53): M (33), F (20)	NR	72.3	M
Clark, 2009	Factors related to Pt' willingness and capacity to undertake effective HF SC.	QUAL (ID)	Canada	SSI	Quota	Pt (42): M (27), F (15), Cg (30)	II/III (42)	76	M
Conard, 2006	Economic burden and the health status of HF Pt	QUANT (Longitudinal)	USA	QUEST	Convenience	Pt (539): M (413), F (126)	I (226) II (228) III (28)	59. 6	H
Cortis, 2007	Needs of older HF Pt	QUAL (ID)	UK	SSI	Convenience	Pt (10): M (5), F (5)	II (2) III (4) IV (4)	NR	M
Crowder, 2005	Impact of symptom management programs on SC	MM	USA	QUEST & SSI	Purposive	Pt (15): M (4), F (11)	III (12)	70	M
Darling, 2013	Factors related to care-seeking delay	QUANT	USA	QUEST	Convenience	Pt (1271): M (674), F (597)	NR	73	H
De Smedt, 2012	The role of medication beliefs and perceptions in coping with ADEs	QUANT (Descriptive)	Netherlands	QUEST	Convenience	Pt (250): M (159), F (91)	NR	69.6	M
de Souza, 2011	Salt preference in HF Pt	QUANT	Brezil	QUEST & Scale	Conveniance	Pt (38): M (26),	II & III	60	M

Table 3.2 (*continued*)

First author/ year	**Primary Focus**	**Methods**	**Country**	**Data collection method**	**Sampling**	**Participants**	**NYHA Class**	**Mean age**	**Scoring MMAT**
						F(12)			
Dickson, 2013	The influence of cultural beliefs and social factors on SC practices	MM	USA	SSI & QUEST	Purposive homogenous	Pt (30): M (18), F (12)	II (10) III (20)	59.6	M
Eldh, 2004	The meanings of participation and nonparticipation in health care	QUAL (Hermeneutic phenomenology)	Sweden	Narrative interviews	Purposive	Pt (10): M (5), F (5)	II/III (10)	74	M
Evangelist, 2003	Compliance behaviors	QUANT (Descriptive)	USA	QUEST	Convenience	Pt (70): M (67), F (3)	III (42), IV (28)	68.6	M
Evangelist, 2001	Gender differences in health perceptions	MM	USA	SSI & QUEST	Convenience	Pt (32): M (16), F (16)	I (12), II (28), III (47), IV (12)	52	M
Farrell, 2011	The impact of psychosocial variables and beliefs on SC	QUANT (Descriptive)	USA	QUEST	Convenience	Pt (105): M (65), F (40)	I (23), II (47), III (34), IV (1)	57.4	M
Freydberg, 2009	The influence of work and place on SC	QUAL (ID)	Canada	SSI	Quota	Pt (42): M (27), F (15); Cg (30)	II/III (42)	76	M
George, 2006	Predictors of refill non-adherence	QUANT (Descriptive)	Canada	QUEST	Convenience	Pt (350): M (243), F (107)	I (158), II (135), III (45), IV (I)	61.7	M
Granger, 2013	Pt' perceptions of the relationship between symptoms and medicines	MM	USA	SSI & QUEST	Convenience	Pt (10): M (5), F(5)	II-IV (10)	67	M

Table 3.2 (*continued*)

First author/ year	Primary Focus	Methods	Country	Data collection method	Sampling	Participants	NYHA Class	Mean age	Scoring MMAT
Heo, 2009	Pt' perceptions on nutrition and dietary adherence	QUAL (Descriptive)	USA	SSI	Convenience	Pt (20): M (14), F (6)	II (6) III/IV (14)	58	M
Heo, 2009	Quality of life in HF Pt	QUAL (ID)	USA	SSI	Convenience	Pt (20): M (14), F (6)	II (6), III (8), IV (6)	58	M
Hicks, 2003	Self-management decision influences	QUANT (Descriptive)	USA	QUEST	Convenience	Pt (38): M (28), F (10)	I/II (5) III (21), IV (12)	60.7	M
Hodges, 2009	Factors impacting readmissions of older Pt	MM	USA	SSI & QUEST	Convenience	Pt (41): M (23), F (18)	NR	75.5	M
Imes, 2011	Partners' experiences of living with severe HF	QUAL (Descriptive)	USA	SSI	Convenience	Cg (14): M (3), F (11)	III/IV (14)	64.8	M
Jurgens, 2009	Factors related to symptom recognition and response among HF elders	MM	USA	QUEST & SSI	Convenience	Pt (77): M (40), F (37)	III/IV (62)	75.9	M
Kaholokul, 2007	Pacific Islanders' perspectives on HF SC	QUAL (ID)	USA	FG	Convenience	Pt (11): M (5), F (6); Cg (25)	NR	Pt: 65.9 Cg: 50.5	M
Leeming, 2014	The impact of HF on Pt' lives	QUAL (ID)	UK	longitudinal interviews	Convenience	Pt (5): Cg (5), HCP (5)	IV (5)	NR	M
Lynga°, 2013	Perceptions of transmission of body weight and telemonitoring	QUAL (Phenomenography)	Sweden	SSI	Purposive	Pt (20): M (15), F(5)	NR	74	M
Macabasco-O'Conne, 2008	SC behaviors in indigent Pt	MM	USA	SSI & QUEST	Convenience	Pt (65): M (29), F(36)	I (3), II (23), III (24),	59	H

Table 3.2 (*continued*)

First author/ year	Primary Focus	Methods	Country	Data collection method	Sampling	Participants	NYHA Class	Mean age	Scoring MMAT
							IV (15)		
Mahoney, 2000	The illness experiences	QUAL (Focused ethnography)	USA	SSI & QUEST	purposive	Pt (16): M (12), F (4) Cg (12)	II (7), III (5)	Pt: 67.7 Cg:54.6	M
Matlock, 2010	Pt' perspectives on decision making	QUAL (Descriptive)	USA	SSI	Convenience	Pt (22): M (6), F (16)	II (10), III (11), IV (1)	69.4	M
Molloy, 2009	Illness beliefs in older HF Pt	QUANT (Descriptive)	Scotland	QUEST	Purposive	Pt (58): M (33), F (25)	II (34), III (24)	80.2	M
Mooney, 2003	The needs of HF Pt	QUAL (Descriptive)	Australia	SSI	Convenience	Pt (11)	I (3), II (4), III (2), I-II/ III-IV (2)	NR	M
Pattende, 2007	Experiences of living with HF	QUAL (Phenomenology)	Scotland & Ireland	SSI	Purposive	Pt (36): M (23), F (13); Cg (20)	I-IV	67.8	H
Rhodes, 2002	Impact of HF on older women's lives	QUAL (Descriptive Phenomenology)	USA	SSI	Convenience	Pt F (5)	II (5)	78.6	M
Rocha, 2009	Predictors of dropout from a program	QUANT (Descriptive)	Uruguay	QUEST	Random	Pt (56): M (40), F (16)	I (21), II (26), III (9),	68.5	H
Rodriguez, 2008	Pt' experiences and knowledge of HF	QUAL (ID)	Pittsburgh	SSI	Random	Pt (25): M (24), F (1)	I (2), II (13), III (9), IV (1)	70.4	H
Ryan, 2009	Experience of living with HF	QUAL (hermeneutic-phenomenology)	Ireland	SSI	Purposive	Pt (10): M (7), F (3)	III–IV (10)	68.9	M
Scotto, 2003	Factors influencing adherence	QUAL (Hermeneutic phenomenology)	USA	SSI	Convenience	Pt (14): M (9), F (5)	NR	63	H

First author/ year	Primary Focus	Methods	Country	Data collection method	Sampling	Participants	NYHA Class	Mean age	Scoring MMAT
Selman, 2007	Pt' and Cg' preferences regarding future treatment modalities	QUAL (ID)	UK	SSI	Purposive	Pt (20): M (16), F (4); Cg (11); HCP (12)	III (14), III/IV (2), IV (4)	69	M
Sethares, 2014	Delay in seeking care	QUANT (Descriptive)	USA	QUEST	Purposive	Pt (131): M (73), F (58)	III (117)	77	H
Simpson, 2000	Barriers to drug use	QUAL (ID)	Canada	FG	Convenience	Pt (318): M (213), F (105)	I (63), II (192), III (42), IV (3)	67	M
Stawnychy, 2014	Using Brief Motivational Interviewing	QUAL (Case study)	USA	Motivational Interview	purposive	F (1)	IV	22	M
van der, Wal, 2007	Pt' beliefs about compliance	QUANT (Descriptive)	Netherlands	QUEST	Convenience	Pt (954): M (592), F (362)	II/III (915)	71	M
van der Wal, 2009	Pt' motivations for compliance	QUAL (Descriptive)	Netherlands	SSI	Convenience	Pt (15): M (9), F (6)	II (7) III (7) IV (1)	70	M
Whitty, 2012	The characteristics of desirable management programs for HF Pt	QUAL (ID)	Australia	SSI	purposive	Pt (12): M (9), F (3)	I (2), II (1), III (3), IV (6)	61	M
Zambroski , 2003	The experience of HF Pt	QUAL/ID	USA	SSI	Purposive theoretic	Pt (11): M (5), F (6)	NR	67	H

Abbreviations: ADE, adverse drug events; Cg, lay caregiver(s); F, Female; FG, focus group; GT, Grounded Theory; HCP, heath care professionals; H, high; HP, health professionals; ID, interpretive descriptive; LSD, low sodium diet; L, low; M, Male; M, medium; MM, mixed-methods; NR, not ported; MMAT, Mixed Methods Appraisal Tool; NYHA, New York Heart Association; Pt(s), patients; SC, self-care; SSI, semi-structured interview; QUAL, qualitative; QUANT, quantitative; QUEST, questionnaire

As we will show, there were multiple and bi-directional interactions between HF patients' values and self-care decision-making (see summary of themes in Appendix N):

(1) The effects of HF influenced which values patients prioritized

(2) Values influenced HF self-care behaviors; and

(3) Self-care behaviors influenced the values patients prioritized.

We will first examine how values became more or less important before moving to examine each of these three processes.

3.1. How values work: values becoming more or less influential

The mechanisms affecting self-care decision-making were identified in a number of studies (Clark et al., 2009, Cortis and Williams, 2007, de Souza et al., 2012, Hicks and Holm, 2003, Scotto, 2003, Stawnychy et al., 2013 and Zambroski, 2003) via two complex processes: prioritizing values and blocking values. These two processes served to modify central aspects of self-care decision-making in phases, for example, relatively small differences in the processes could lead to marked changes in the values they influenced.

3.1.1. Prioritizing values

Individual values do not affect self-care decision-making in a direct linear fashion (Hicks and Holm, 2003; Scotto, 2003 and Zambroski, 2003). Rather, the process of decision-making during HF is circular, with values playing an important role in self-care decisions and vice versa. Decisions are made based on the ways in which individuals prioritize and reconcile seemingly competing values. For each self-care decision, at different time points, several values are involved and some are compatible with each other – while others are in conflict. For example, patients prioritized particular values not only in response to competency-based factors (e.g. knowledge, skills, and experience) (Bentley et al., 2005 and Scotto, 2003), psychological factors

(Leeming et al., 2014), beliefs (e.g. being, “too old to change some habits” [Scotto, 2003, p. 161]), but also as a function of the specific context of HF (Mahoney, 2000 and Scotto, 2003). Indeed, the symptoms of HF lead some to prioritize particular values and demote others (Barnes et al., 2006, Evangelista et al., 2001, Leeming et al., 2014 and Mahoney, 2000) (Fig. 3.2)

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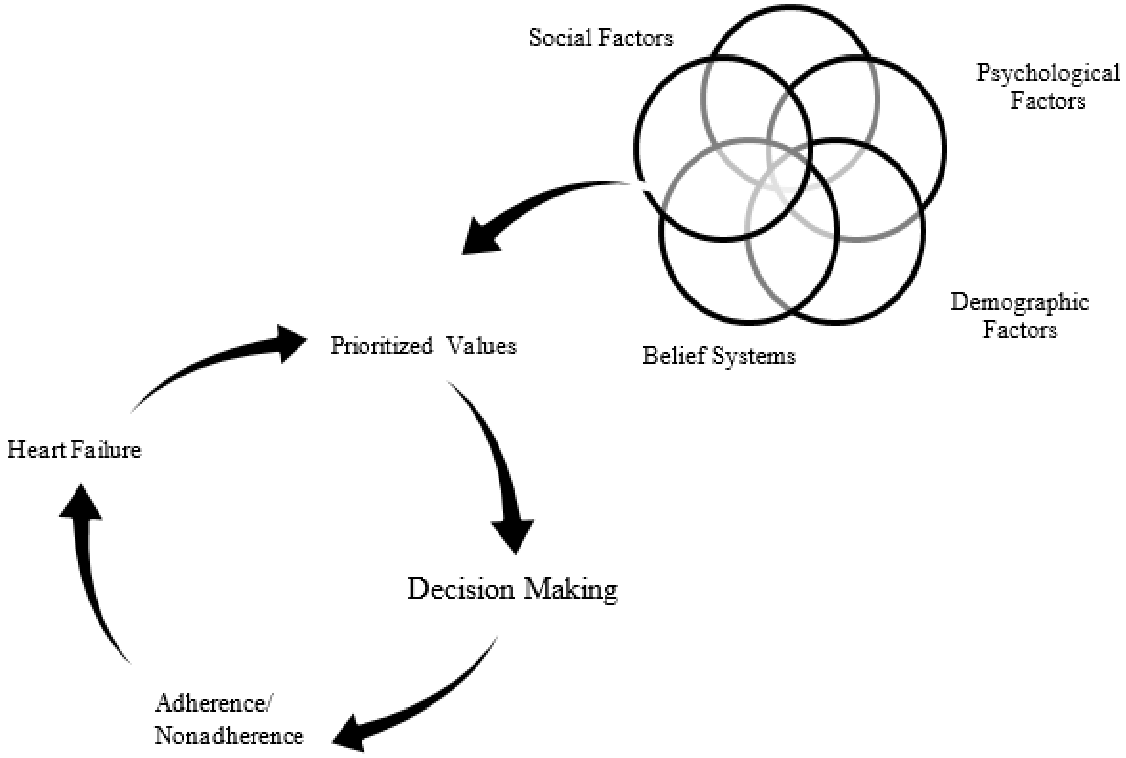

Figure 3.2

A Circular-Flow Diagram

The iterative nature of this process is evident in decision-making about self-care behavior; decisions are based in part on the value(s) prioritized at that particular point. However, the outcomes of decisions can also consequently impact the patients’ HF status. This may cause the patient in turn to change the priority of their values. For instance, in one situation a patient may prioritize the values of pleasure and socialization and choose to attend a particular social event which will likely impact non-adherence to one's diet/fluid restrictions, such as dinner at a restaurant (Heo et al., 2009a and Simpson et al., 2000). Indeed, the patient may maintain former prioritized values and decisions, even when the consequence of the decision may be deteriorating health or worsening HF symptoms (Bennett et al., 2005). In turn, actually experiencing this deterioration may influence patients' prioritization of their values. In other words, in experiencing this situation again, a patient may prioritize the values of being healthy and self-care adherence to maintain or improve health status (Bennett et al., 2005 and Conard et al., 2006).

3.1.2. Blocking values

Sometimes patients were discouraged from expressing values in their behavior. When a HF patient experiences a value being blocked, for example, their desire to fulfill that value can, paradoxically, be increased (de Souza et al., 2012, Scotto, 2003 and Zambroski, 2003). Blocking pleasure-seeking (such as the pleasure of eating salty food) may not only produce negative effects such as frustration and disappointment (de Souza et al., 2012, Evangelista et al., 2001 and Zambroski, 2003), but may also generate an increase in desire for this seemingly "prohibited" pleasure (Bennett et al., 2005, Boren, 2001, de Souza et al., 2012 and Scotto, 2003). Patients reported, for example, that their cravings for high sodium foods unexpectedly increased when they were instructed to reduce dietary intake of foods high in sodium (Bentley et al., 2005). Similarly, patients with HF may have a greater preference to remain at home even when hospitalization is required (Zambroski, 2003). This reaction is likely a response to an external party indicating an aspect of self-care and involves the denial of a particular behavior. For example, a patient who is told by a health professional that they need hospital treatment may resist this suggestion when staying home fulfills a comfort value (Leeming et al., 2014). As such, the processes in which values influenced self-care were fluid and iterative.

3.2. ***Key processes***

The specific ways in which values were prioritized and blocked will now be addressed. The synthesized studies provided important insights into the three iterative and overlapping processes involving patients' values, heart failure and its self-care decision-making.

3.2.1. The impacts of HF on individuals' value priorities

The symptoms of HF challenge patients' capacities to pursue values that are important. Although this may differ substantially across patients, one of the most consistently cited values influenced by the context of HF is achievement (Bosworth et al., 2004, Mahoney, 2000 and Zambroski, 2003) – that is, individuals' sense of, and satisfaction in, their capability to achieve desired results (Schwartz et al., 2012). Failure to prioritize achievement has been described as "not being able to do" (Hodges, 2009 and Ryan and Farrelly, 2009) and being "handicapped" (Mahoney, 2000). In the context of HF, the extent of this perceived incapability is broad as HF constrains a wide range of activities, including the ability to wake up (Bennett et al., 2000 and Bennett et al., 2005), to maintain a household (Boren, 2001 and Pattenden et al., 2007), and practice spiritual traditions such as service to God (Mahoney, 2000), which is itself a traditional value. These further limit patients' independence, which is one form of the value of self-direction (Boren, 2001, Ryan and Farrelly, 2009 and Zambroski, 2003).

A desire to terminate one's own life could also result from patients' inability to fulfill key values such as achievement (Selman et al., 2007 and Small et al., 2009). Hence, in the context of HF, dying could emerge as a prioritized and important value, particularly in older adults with NYHA Class IV and poor mobility (Selman et al., 2007 and Small et al., 2009). Conversely, in situations where patients perceived that their lives were in jeopardy, the value of being alive became more important (Crowder, 2005 and Imes et al., 2011). Following the prioritization of this value, patients raise their hopes and endeavor to adhere. As one patient noted, "I know my limitations and try to live as high a quality of life as I can" (Crowder, 2005, p. 56).

3.2.2. *The impact of value priorities on self-care*

Just as HF has profound (and often unexpected) effects on patients' values, those values exert a clear influence on the ways patients perform self-care (Fig. 3.3). The nature of this influence is complex as some patients are motivated largely by personal considerations, and others predominantly by a sense of wider duty and obligation to others. It is therefore useful to divide their values into two groups of overarching themes: *self-related values* and *other-related values.*

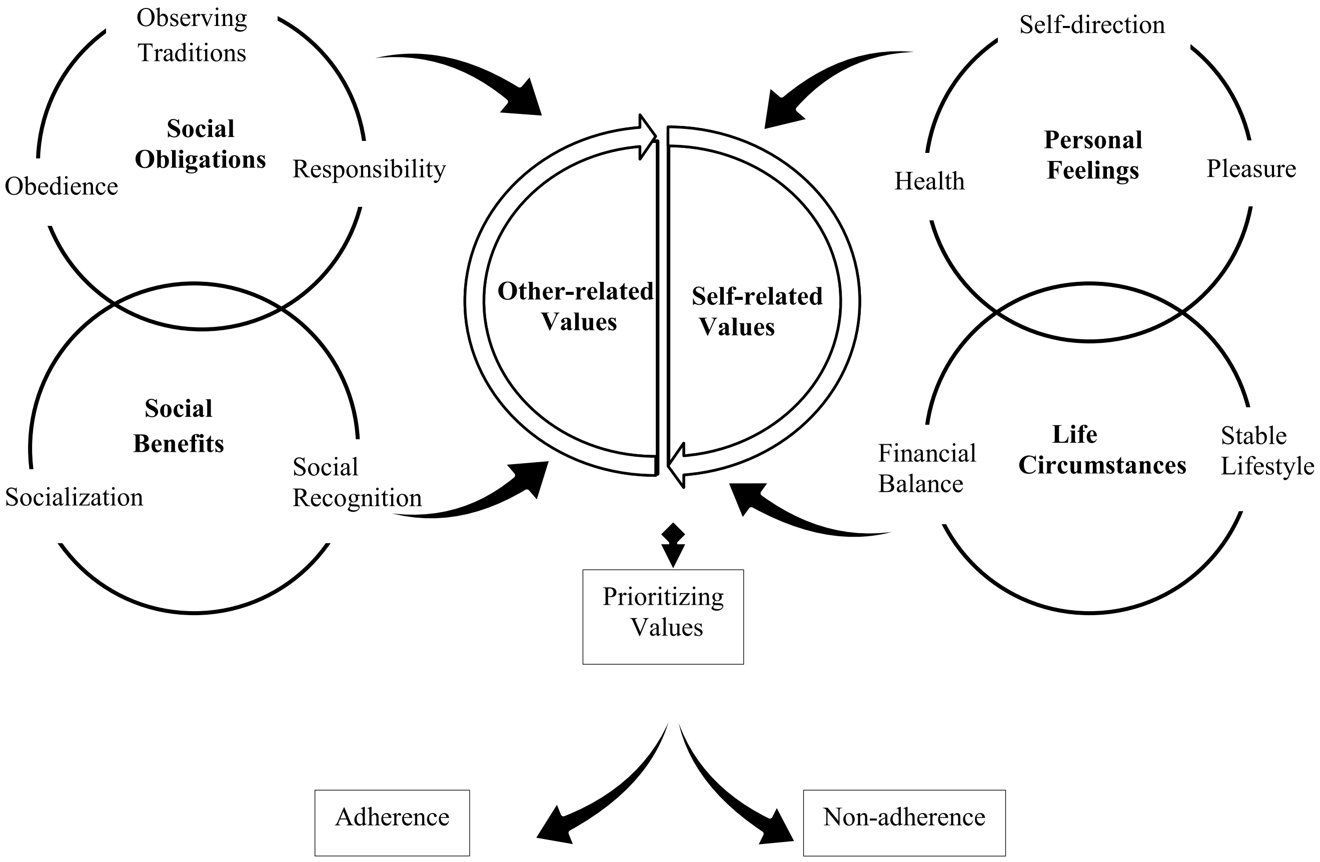

Figure 3.3 *The Value-Laden Self-Care Decision-Making Process*

3.3. Self-related values

This broad category of self-related values is concerned with HF patients' perceptions and sense of self, which may have a significant impact on practices related to HF self-care. Some of the values that offer the most powerful motivations are those tied directly to intimate personal feelings. Other values related to individuals' life circumstances may also play a role, as noted below.

3.3.1. Personal feelings

Among the self-related values related to patients' feelings about themselves, three were more common and important: self-direction, pleasure, and being healthy. Self-direction is a core and gendered value, particularly evident among men (Cholowski and Cantwell, 2007), that guides patients in choosing self-care strategies that they instigated (Boren, 2001, Cholowski and Cantwell, 2007 and Farrell et al., 2011, Molloy et al., 2009, Heo et al., 2009a and Mooney and Boxer, 2003). While self-direction is not explicitly described in the literature, this value was inferred via references to volitional (Cholowski and Cantwell, 2007) and active decision-making and patients' autonomy (Bosworth et al., 2004, Evangelista et al., 2001, Farrell et al., 2011 and Pattenden et al., 2007), independence (Barnes et al., 2006 and Whitty et al., 2012), mastery, curiosity (Mahoney, 2000), and the need for control (Crowder, 2005, Eldh et al., 2004 and Mahoney, 2000). Self-direction motivates patients intrinsically, not only to acquire knowledge, but also apply knowledge in relation to their self-care (Evangelista et al., 2003, Evangelista et al., 2001 and Scotto, 2003).

The fulfillment of these values, which involves agency on the individual's part, could help patients pursue other values that offered specific benefits. Pleasure, for example, was frequently cited in different self-care behaviors particularly in relation to diet (Bennett et al., 2005, Bentley et al., 2005 and Scotto, 2003), which is "a source of pleasure" (Heo et al., 2009a) for some patients with HF. Pleasure was also pursued in terms of having an undisturbed sleep (Bennett et al., 2000, Boren, 2001 and van der Wal et al., 2007) or in terms of achievement and a sense of productivity at work (Clark et al., 2009, Mahoney, 2000 and Scotto, 2003). This could lower adherence to self-care recommendations (Bennett et al., 2000, Boren, 2001 and van der Wal et al., 2007); for example, when the pursuit of pleasure (going out socially) lead to a patient failing to adhere to consuming diuretic medication or prioritizing work obligations over self-care responsibilities.

While it is expected that patients are guided by the value of being healthy from the time they are diagnosed with HF, in some cases, being healthy is prioritized only after experiencing severe consequences of non-adherence to medication. For example, several studies identified that patients sought to be healthy by adhering to their prescribed medicine regimens, but may not adhere to all components of self-care recommendations, particularly related to dietary habits (Scotto, 2003 and van der Wal et al., 2010). Generally, the values of being healthy and being alive were seen to be compatible and contribute to adherence (Hodges, 2009, Simpson et al., 2000 and Stawnychy et al., 2013).

3.3.2. Life circumstances

Less important to HF self-care, but still influential as motivators of self-care behavior, are values related to patients' life circumstances: maintaining a healthy lifestyle and financial balance. The first of these has special relevance to HF patients: the condition of HF requires an essential and constant change in lifestyle. This value was evident in patients' desires to have a "normal life" (Boren, 2001, Pattenden et al., 2007 and Rodriguez et al., 2008). Pursuing this value may conflict with adherence to self-care, particularly in relation to dietary changes and diuretic therapy – for example adjusting and changing one's lifestyle is seen by patients to be "hard", and that it is "not [an] easy" task (Boren, 2001 and Scotto, 2003) to change one's routines.

For some patients, financial balance in their life was prioritized and also guided behaviors (Conard et al., 2006, Crowder, 2005, Jurgens et al., 2009, Kaholokula et al., 2008, Macabasco-O'Connell et al., 2008, Pattenden et al., 2007, Scotto, 2003 and van der Wal et al., 2010). The emergence of financial balance is an example of a broader value of security and can be a self-related value that could impede self-care behavior (Crowder, 2005, Kaholokula et al., 2008, Macabasco-O'Connell et al., 2008, Pattenden et al., 2007 and Scotto, 2003). Indeed, medication and diet non-adherence and hospitalization avoidance were preferred behaviors among HF patients who perceived that purchasing medications and healthier food were obstacles to financial balance (Darling et al., 2013). In some cases, financial balance was found to be compatible with the value of family security (Hodges, 2009) as this allowed patients to maintain a legacy for their family. As such, in order to protect their family's resources, patients may adjust their income and expenses, which directs them toward non-adherence in self-care.

3.4. Other-related values

A second broad category of values related to the ways in which patients with HF sought to interact with society. These values take two broad forms: those related to benefits received from society (social benefits), and those related to social obligations.

3.4.1. Values related to social benefits

The social benefits HF patients seek came in at least two forms: the ways in which others view them (social recognition) and the ways in which others engage with them (socialization). In terms of social recognition, as the condition of HF can interfere with pursuing this value, non-adherence as a compensatory response is frequent (Cortis and Williams, 2007; Eldh et al., 2004, Leeming et al., 2014, Scotto, 2003 and Simpson et al., 2000). For example, when HF contributes to decreasing physical capability, some patients had a strong desire to be recognized in terms of their earlier public competency image (Leeming et al., 2014 and Zambroski, 2003).

As such, a patient may be exhausted and resist fatigue to avoid being perceived as a duty evader (Scotto, 2003). Social recognition is threatened not only by the physical health of patients with HF, but also by situations that they may face, by feeling like a burden to family caregivers (Cortis and Williams, 2007 and Kaholokula et al., 2008) or being disrespected by health-care professionals (Stawnychy et al., 2013). The feelings patients associated with becoming a burden on relatives, friends, or health care professionals related to feeling disrespected, or perceiving themselves as "useless." These conflicted with pursuing the values of self-recognition and were linked to: non-adherence (Cortis and Williams, 2007, Darling et al., 2013, Rhodes and Bowles, 2002 and Whitty et al., 2012), isolation from relatives and friends (Dickson et al., 2013), and delays in seeking help and hospitalization (Eldh et al., 2004 and Stawnychy et al., 2013). Studies of HF patients pursuing socialization center on activities such as eating out or spending time with family and friends (Bentley et al., 2005, Scotto, 2003 and van der Wal et al., 2010). These activities tended to interfere with and reduce adherence to HF self-care, particularly to a sodium limited diet or to diuretic medicines (Bentley et al., 2005, Scotto, 2003 and van der Wal et al., 2010). Additionally, patients reported that choosing to adhere to self-care could reduce the likelihood of participation in social events (Barnes et al., 2006, Bennett et al., 2005, Bennett et al., 2000, Bentley et al., 2005, Dickson et al., 2013, Heo et al., 2009b, Leeming et al., 2014, Leeming et al., 2014, Simpson et al., 2000 and Zambroski, 2003). However, this could consequently lead to social isolation (Bentley et al., 2005, Dickson et al., 2013, Leeming et al., 2014 and Mahoney, 2000).

3.4.2. Values related to social obligations

Patients with HF may also be motivated by a sense of social obligation to others and society at large. At the individual level, these values appeared as a sense of responsibility and at the society level, take two forms of observing traditions, and obedience. Responsibility emerged as an important value in self-care decision-making (Freydberg et al., 2010, Kaholokula et al., 2008, Lynga et al., 2013 and Rocha et al., 2009). In the context of HF, some patients value their responsibilities more than their self-care activities when there is interference between self-care behavior and duties, such as child/grandchild care (Kaholokula et al., 2008), work responsibilities, family support, and family obligations (Freydberg et al., 2010, Kaholokula et al., 2008, Lynga et al., 2013 and Mahoney, 2000). For dutiful people to whom fulfilling responsibilities takes precedence, those duties can be seen as obstacles to HF self-care (Darling et al., 2013, Freydberg et al., 2010, George and Shalansky, 2007 and Kaholokula et al., 2008). There were indications, for example, that patients may ignore their symptoms and delay seeking help (Kaholokula et al., 2008 and Scotto, 2003). This was noted particularly in patients from rural communities (Clark et al., 2009). In this context, the value of social responsibility may be compatible with other deeper values associated with tradition (notably maintaining traditional gender work roles) (Barnes et al., 2006 and Clark et al., 2009), pleasure, social recognition (avoiding judgment by neighboring farmers, or colleagues) (Freydberg et al., 2010, George and Shalansky, 2007 and Scotto, 2003), and independence (Bosworth et al., 2004, Freydberg et al., 2010, Stawnychy et al., 2013 and Whitty et al., 2012).

The maintenance of tradition – that is, “respect, commitment, and acceptance of the customs and ideas that one's culture or religion provides” (Schwartz et al., 2012) – is a value that contributes to decisions about self-care. For example, in a study with indigenous people (Kaholokula et al., 2008), tradition guided patients’ behaviors, specifically with respect to willingness to visit a doctor or preferences for traditional medicines over Western medical services. In contrast, Indigenous patients from another culture had traditions that passed on trust in physicians

(Kaholokula et al., 2008). Hence traditions contributed to both self-care adherence and non-adherence.

Likewise, the value of obedience could guide patients with HF in their self-care decision-making. Indeed, some preferred to simply follow others' instructions (Artinian et al., 2002, Dickson et al., 2013, Kaholokula et al., 2008, Matlock et al., 2010 and Sethares et al., 2014) – a stance that the literature labels as being passive (Matlock et al., 2010). This tended to be noted in women (Cholowski and Cantwell, 2007; Scotto, 2003), and those, experiencing physical, emotional, or social supports, uncertainty surrounding treatment, worsening symptoms, or life-threatening emergencies, who were more reliant on others (Barnes et al., 2006, Farrell et al., 2011, Scotto, 2003 and Zambroski, 2003). Although it would seem that HF patients who prioritize obedience would comply with health professionals' advice, non-adherence was also common and such binary views should be avoided. Indeed, being adherent or non-adherent depended upon whom patients trusted the most. Patients may trust their physician (Farrell et al., 2011, Kaholokula et al., 2008, Matlock et al., 2010 and Simpson et al., 2000), but they may also heed the beliefs of family members or cultural or religious teachings (Barnes et al., 2006, Kaholokula et al., 2008, Matlock et al., 2010 and Scotto, 2003) regarding adherence or non-adherence. For example, family members may elicit a "passive response" by discouraging HF self-care (saying things like: "Don't take any pills" or "Don't worry"); this may contribute to delays in seeking help when worsening symptoms occur (Kaholokula et al., 2008, p. 284).

3.4.3. The impact of self-care on the pursuit of prioritized values

While individual values influence self-care decision-making, self-care activities conversely influence the extent to which patients can pursue their prioritized values both positively and negatively (Granger et al., 2013, Heo et al., 2009a and Simpson et al., 2000). Taking medication, for instance, may improve patients' status and allow them to pursue their values, such as being healthy, having a joyful life, and being independent. However, medication adherence may also interfere with prioritizing their other values. For example, because of the frequent need to urinate due to diuretic use, patients may stay at home and refuse to travel (Bennett et al., 2005, Bennett et al., 2000 and Leeming et al., 2014), go to unfamiliar places (Bennett et al., 2005), or attend social events, which is in conflict with the pursuit of the values of socialization, social recognition, and pleasure (Barnes et al., 2006, Bennett et al., 2005 and Leeming et al., 2014); yet, the reluctance to leave home is compatible with comfort (because of accessible bathroom at any time). As one patient states, "[Following professional recommendations] is difficult and it is sad…. Nothing tastes good and you get tired of it…. I think that is a crime because I like to eat! We like to go eat out" (Boren, 2001, p. 76).

4. **Discussion**

This is the first mixed-methods systematic review to document the complex range of ways through which patients' values influence HF self-care. Drawing data on self-care from past qualitative and quantitative studies, findings illustrated that HF and its symptoms affected values but that these values in turn affected HF self-care – which itself also affected both HF and value priorities. These results provide compelling evidence that future interventions to promote effective HF self-care must address and incorporate patients' values, but also be sensitive to the cyclical ways in which HF, its self-care and values effect and respond to each other.

Nurses are especially well placed to assist patients deal with conflicts that arise between their values and self-care recommendations and should encourage patients to reflect on, be aware of, express and reconcile these values in their self-care (Cortis and Williams, 2007).

The centrality of patient values to their self-care is particularly noteworthy because past interventions focused on improving patients HF self-care have done surprisingly little to incorporate patient values into the components or contents of their interventions (Clark and Thompson, 2008). To ensure that future interventions are more responsive in integrating patient values (Clark and Thompson, 2012), those designing interventions should involve patients in the early stages of intervention design and develop interventions to be more responsive to patient values and how these affect self-care. Care should address the complexities of how the severity of HF symptoms may moderate patient values and approaches to self-care. To better integrate such values into care, the full range and scope of the iterative ways that values can influence HF self-care, as illustrated by this review, should be understood and used to inform care. While this review does not provide prescriptive guidance on how to do this, it can be used to attune health professionals to this complexity and allow both the ongoing effects of HF on values and vice versa to be better appreciated and incorporated into care. Findings from the review indicate that patient values cannot be assumed to be normative, fixed and similar to those of the health professional. Open discussion in nursing care interactions should be encouraged to make these aspects more explicit while nurses should present self-care domains (for example medication consumption) as ideologically neutral and non-stigmatized. Acknowledgment should be made that it is acceptable and normal for patient values to be diverse and even in conflict with those held by health professional. Wider involvement of families in these more open consultations could support better discussion and incorporation of patient values into care recommendations (Clark et al., 2014, p. 95).

In terms of future research, although compelling arguments can be made that values are an important influence on HF self-care behaviors, relatively few dedicated quantitative or qualitative studies have examined the variety of ways in which specific values influence specific facets of HF self-care behaviors. Although this review is the first to crystallize and synthesize data from existing research, future studies are needed to develop valid measures of patient values to support more systematized and objective assessment of these values in healthcare. More knowledge is also needed of variations in different populations (by age, sex or location) and the role particular pivotal values have on HF self-care behaviors. Future interventions to promote effective HF self-care should incorporate and respond to patient values in interventions. Interventions evaluated in RCTS to date have done little ostensibly to incorporate responsiveness to patient values into interventions (Clark and Thompson, 2008 and Clark and Thompson, 2012). The findings from this review could be used as a framework to design interventions that more formally recognize and respond to patient values around HF self-care and, in time, more effective and consistent interventions.

5. **Limitations**

As with many reviews, our search was limited to only English language, peer-reviewed journals or dissertations published from the year 2000 and onwards. Limitations were also evident in the included studies. One particular issue was related to the lack of studies that explicitly stated addressing patients' "values." Consequently, we extracted data in studies related to values based on the theoretical discussions of Rokeach and Schwartz. Another constraint was the lack of studies containing data on caregivers and health-care professionals' perspectives on patients' values.

Converting the quantitative data to qualitative data allowed for inclusion of more data from published studies although this process of qualitizing also provided limited context and depth for these insights (Sandelowski, 2001). The findings are also constrained given the majority of the studies included were conducted in high income countries. Few described the characteristics of those who declined to participate in the study

6. Conclusion

Values are integral to how patients approach and undertake HF self-care. These values both effect and respond to this self-care and the severity of HF symptoms. Values extend to those relating to the self and others and incorporate a notable range of personal, life, and social dimensions. Values cannot be assumed to be fixed, normative or similar to those held by nurses and other health professionals. Future interventions to improve HF self-care must address and respond to the complexity of these values and how they influence patient behavior.

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Chapter 4: Making Sense of Heart Failure Patients' Views on Their Value-Based Self-Care Decisions[10]

Abstract

Aims. The aim of this study was to explore how participants living with heart failure make sense of their values and how those values are expressed in self-care decision-making.

Background. HF is a disabling and degenerative syndrome with a 50% five-year mortality, which creates a burden for patients, their families, and the health care system. Effective self-care helps patients live longer and have a better life; nevertheless, adherence to self-care recommendations is low and poor among HF patients. Factors affecting HF self-care decisions remain unclear and little is known about the influence of patients' values on these choices.

Design. An Interpretative Phenomenological Analysis approach was employed to analyse interview data.

Methods. Semi-structured interviews were conducted with 12 HF patients with NYHA class II and III between January 2016 and December 2016 from two urban sites in Western Canada.

Findings. Analysis of data uncovered two overarching themes addressing aspects of values and decision-making: directness and complexity. Two main types of values, functional and emotional values, are involved in both adherent and non-adherent decisions. Each type can be further categorized into three sub-groups: self-related values, other related values, and health professional-related values. The relationship between aspects of participants' heart failure and their values was complex and indirect; in the context of HF, the priorities assigned to values

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[10] This study will be submitted to the *Journal Advanced Nursing* and is formatted according to the style required by the journal

could change, and those changes themselves vary for different self-care decisions. Values may also be in flux, the pursuit of the prioritized values may be in conflict with physical ability, and the ways in which values are pursued can be changed.

Conclusions. Given the complex mechanisms underlying value-laden decision-making processes, further research is warranted to address interventions that may support those complex decisions. In light of the findings of this study, patients can be supported by helping them to find alternative ways to pursue their values.

Why is this research or review needed?

- Values are the foundations of patient decisions but have been overlooked or superficially addressed in past research into HF self-care decision-making.
- Previous studies refer to patients' values wrongly – using the concept interchangeably with *attitudes* and *preferences*.

What are the key findings?

- Two forms of values, functional and emotional, influence patients' self-care decisions.
- While functional values are associated with actions, emotional values are associated with emotions. Both types can be related to self, others, or health-care professionals, and also influence each other.
- Although HF patients may continue to prioritize values they have maintained for years, the effects of HF symptoms and the self-care behaviors needed to manage them, compel patients to deviate from the values that they held prior to their HF diagnosis and the priorities assigned to these values.
- Negative emotions, low adherence to self-care recommendations, and defiance against self-care recommendations occur when physical limitations caused by HF conflict with patients values.
- In relation to self-care performance, the prioritization of values can be selective and differential in relation to different components of self-care behavior, and often varies over time and situation.
- Depending on the patients' HF status, values that are involved in self-care decisions can be in flux.

How should the findings be used to influence policy/practice/research/ education?

- In order to provide patient-centered care, nursing practice should go beyond asking patients' preferences for their involvement in care decisions. Patients' values instead need to be explored as the foundation for making self-care decision, and nursing care needs to be planned accordingly.
- Patients' values related to different components of self-care should be assessed separately.
- Patients may need privacy to express some of their values. Particular forms of communication are required for nurses to gain an in depth understanding. More research is required for this.
- The terms *someday* or *occasionally* are terms that can lead us to explore occasional nonadherence and how particular values are related to those decisions. Such understanding may facilitate effective support in delivering patient-centered care.

Introduction

Decisions in nearly all crucial aspects of life – from choices about relationships to complex health decisions – are informed by a person's values. However, while studies in social psychology have focused on the role of values in determining and predicting human behavior, this influence is not well described in the self-care decisions made daily by patients with heart failure (HF).

HF is a disabling and degenerative syndrome with a 50% five- year mortality rate, which creates a burden for patients, their families, and the health care system (Jovicic et al., 2006; McAlister, Stewart, Ferrua, & McMurray, 2004; Roger et al., 2012). Effective HF self-care can help patients live longer and have better lives (Seto et al., 2011; Wang, Lin, Lee, Wu, 2011), but may be complex to undertake effectively (Clark, 2009). Effective HF self-care requires management of complex medication regimen as well as regulation of fluid, alcohol and salt intake; regular physical activity; and prompt help seeking (Lee, Tkacs, & Riegel, 2009). Consequently, patient adherence to self-care recommendations is frequently poor (Marti et al., 2013) among HF patients, and the extent of adherence varies for each component of self-care: 38% to 76% for adherence to a medication regime (Riegel et al., 2011; Nieuwenhuis, Jaarsma, van Veldhuisen, & van der Wal, 2012), 10% to 40% for adherence to a low-sodium diet (Lainscak et al., 2007), 34%-85% for monitoring daily weight, and 48%-64% for performing routine exercise (Nieuwenhuis et al., 2012).

While a variety of determinants have been examined to identify facilitators and barriers to effective HF self-care behaviors (Siabani, 2013), to predict such actions (Riegel, 2011), and improve outcomes (Heo, Lennie, Moser, & Okoli, 2009; Clark, Savard, & Thompson, 2009), the precise determinants of self-care adherence remains unclear (Riegel et al., 2011). Consequently, efforts to enhance patients' self-care knowledge have not yielded consistent improvements in HF outcomes (Boyde et al., 2011; Clark et al., 2009; Ni et al., 1999; Stromberg, 2005). In addition, while interventions or programs to improve self-care effectiveness are often useful when patients do participate (Crundall-Goode, Goode, & Clark, 2016), a sizable minority of patients’ view participating in educational/interventional/ management programs as being of low value or fail to seek help from health professionals for HF symptoms (Crundall-Goode et al., 2016).

Furthermore, high rates of re-hospitalizations and nonadherence in HF patients may point to the influence of determinants that have not been identified or well understood. Such knowledge is crucial not only because of enduring poor outcomes and their resulting burden on patients, family caregivers, and the health-care system, but also because HF is also common amongst people aged over 65 years– a population that continues to rise in size..

Based on a recent systematic review study (Karimi & Clark, 2016), we distinguish two types of determinants that are involved in the process of self-care decision-making: primary and secondary determinants. The primary determinants – values – influence self-care decisions. This is because patients' self-care behavior proceeds by decision-making, which is a cognitive process of perceiving, processing (information), judging (evaluating the consequences) and deciding (Rowe & Mason 1987), that is driven fundamentally by individuals' *values*. Conceptually, patients' values are defined as core beliefs, which are abstract and subjective in nature and perceived as very significant to individuals. Values guide and shape our perceptions, and as a result, they affect our decisions, actions, and emotions (Nelissen, Dijker, & De Vries, 2007; Rokeach, 1973; Schwartz, 1992).

The secondary determinants; however, are generally not key determinants in predicting decisions (Reis & Judd, 2000); and are influenced by the primary determinants in a variety of ways. Secondary determinants involved in self-care decision-making include bio-behavioral (e.g., attitudes and self-efficacy), physiological (e.g. cognitive status, physical functioning, fatigue, and comorbid conditions), demographic (e.g. age, culture, and gender), and competency-based factors (e.g. knowledge of HF and its symptoms, previous experience, and skills), as well as psychological factors (e.g. depression and anxiety). They also include belief systems (e.g.

perception, confidence), and external factors (e.g. caregivers' support or other social variables) (Dickson, Deatrick, & Riegel, 2008; Dickson, Tkacs, & Riegel, 2007; Moser, & Watkins, 2008).

The importance of patients' values has been recognized, but has only been addressed to a limited extent in relation to HF self-care. In some cases, the term "*values*" is used interchangeably with patients' "preferences" (Sepucha & Mulley, 2009) while the role of values in self-care decisions has been poorly explored. Consequently, it is not clear how best to develop a values-based approach to helping nurses promote effective self-care (Rosenberg, 2016) as well as to improving patients' physical and mental status (Mårtensson, Strömberg, Dahlström, Karlsson, and Fridlund, 2005) and quality of life (Levine et al., 2012; McMurray & Stewart, 2002).

Thus, to take action to address this important gap, this study examined the reported role values had in influencing self-care decisions in HF patients in relation to both familiar or unfamiliar "disease" situations (Clark et al., 2014).

The Study

Aim

The purpose of this study was to explore patients' interpretations of the types of values that were involved in their self-care decisions, and to analyze how those values were reported to be applied to self-care decision-making.

Design

This was a focused study that analyzed data concurrently with a larger study, entitled "Living with Life-threatening Illness: Narratives of Liminality". This study utilized the interpretative phenomenological analysis (IPA) approach, which focuses on understanding the participants' psychological world – in particular, those elements "in the form of beliefs" (Smith

& Osborne, 2008, p.66). IPA is a “double hermeneutic” (p.53) approach. Accordingly, my analysis first involved gaining an understanding of the HF patients’ views of “what the experience of self-care decisions in relation to their values is like” (empathic hermeneutics). Then, it involved researchers’ interpretation of the participants’ accounts (Smith, Flowers and Larkin, 2009) by asking critical questions of the texts (for example: “How does the HF patient attempt to talk about his or her values implicitly or explicitly?” “How and in which conditions or patterns do values influence self-care decision-making?”). This approach was selected because of its central analytic concerns, which is pertaining to the individual’s psychological world and is consistent with the purpose of this study.

Participants

The participants in this study were 12 HF patients (8 men and 4 women; mean age = 69.25 years, SD = 9.34). This number was consistent with the guidelines for IPA studies, which do not set out a specific rule for the sample size; it depends on the level of analysis, reporting and the richness of the individual cases (Smith & Osborn, 2008). To be included in the study, patients: (1) could be of either sex; (2) older than 60 years old; (3) able to speak, read and understand the English language; (4) diagnosed with New York Heart Association class II and III HF. The majority of the participants (Table 4.1) were male (66.7%) and perceived their economic level as middle class. Participants’ education levels ranged from primary (high) school to advanced graduate degrees (PhD). All participants were retired, and none performed any paid work, with the exception of one participant who was casually employed.

Table 4.1

Demographic and Clinical Characteristics of Heart Failure Patients

Demographic and clinical characteristics	N (%)
Age	
Mean	69.25
Sex	
Male	8 (66.7%)
Female	4 (33.3%)
Years after diagnosis	
SD (range)	5.9 (1.5-16)
*Education level**	
≤10 th grade	2 (16.7%)
High school graduate	2 (16.7%)
Vocational diploma	4 (33.4%)
Undergraduate degree	1 (8.3%)
Graduate degree (master's and doctoral level)	2 (16.7%)
Perceived economical level	
High	2 (16.7%)
Middle	8 (66.7%)
Low	2 (16.7%)
Living arrangement	
With spouse	7 (58.3%)
With relatives	2 (16.7%)
Alone	3 (25%)

*One participant's education level was not identified.

Data Collection

Participants[11] were recruited via convenience sampling of eligible patients over nine months between January 2016 and December 2016 from two urban sites in Western Canada: The Heart Function Clinic, located in Edmonton, Alberta and Island Health Authority, located in Victoria, British Colombia. Both centres provide a broad range of services to HF patients. A set of in-depth interviews were conducted for approximately 90 to 120 minutes by a team of

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[11] See appendix P for detailed methodological information

experienced interviewers. This method was appropriate as the personal and in-depth quality of the interviews allowed patients to reveal their underlying beliefs about reality (King & Horrocks, 2010; Schostak, 2006).

The interviews were guided by two sets of values-related questions and HF experience-related questions, and were developed and refined based on previous literature and in consultation with the research team. The importance of including both of these types of questions was also evident in the interview. Although patients sometimes identified and reflected on aspects of their values in response to direct questions, this was not usually the case. More often, values were invoked while patients shared their experiences of living with advanced HF in relation to self-care (Karimi & Clark, 2016). Thus, using this approach to examining implicit or explicit data allowed us to consider an individual as an open system – that is, one in which his or her experiences and values drive decisions, which are also influenced by both individual and contextual factors (Clark & Thompson, 2012; Allen et al., 2012). This prevented us from skewing patients' values without considering their broader context.

These interviews and field notes were audio recorded and transcribed verbatim. The transcripts of semi-structured in-depth interviews, along with audiotapes and field notes, were the data sources that conveyed what was experienced, what was learned through interaction with participants, and what was observed during the interview (Kawulich, 2005).

Ethical Considerations

Ethics approval for this study was obtained from the host Research Ethics Board and adhered to throughout. Interviews were conducted after the informed consent was agreed to and signed, and took place in a location determined by the participants' preferences. The transcripts, audios, and field notes were kept and used anonymously in a secure virtual research environment.

Data Analysis

In line with IPA, the analysis began by reading and re-reading the first transcript several times (Smith & Osborne, 2008). A sustained engagement with the text allowed understanding of the complex meanings of respondents' statements and to go deeper to learn about their values. Then, the patients' comments, including statements, figures of speech (e.g. metaphor, and symbols), and repetitions (Pietkiewicz & Smith, 2014), filler words (Laserna, Seih, & Pennebaker, 2014), silent data (e.g. laughter, silences volume, pitch, pace, tone, repetitions) (Poland, 1995) related to patients' values and their relation to self-care in the participants' quotes were annotated and translated into themes to achieve a higher level of depth and abstraction. The emergent themes in a given transcript were thus listed and clustered according to conceptual commonalities (Smith & Osborne, 2008). The clustering process was constantly checked by re-reading a transcript to make sure that the relationship between themes was accurate (Lee, Lee & Choi, 2010; Fischer, 1999; Schwartz, 2012). The participants' quotes were provided in order to justify related themes. This analysis was continued for the subsequent transcripts and common themes or patterns established using cross-case data analysis. These themes were then prioritized based on the richness of the specific text that highlighted them (Smith & Osborne, 2008). A final table of superordinate themes was created and then woven into a narrative account that included supporting verbatim quotations.

Rigor

In this study, in order to attain and enhance the rigor of the data analysis and interpretation process (De Witt, & Ploeg, 2006), researchers employed criteria and measures as pointed out by Lincoln and Guba (1985), Morse, Barrett, Mayan, Olson, and Spiers (2002), Ratner (2002), and Gilgun (2010). For example, methodological coherence was achieved by establishing the interdependency between research questions and analytic procedures (Morse, Barrett, Mayan, Olson, & Spiers, 2002). The self-correcting method was also practiced (Morse et al., 2002) by listening to the data and moving back and forth frequently between comments, themes, and clusters, as well as by reading transcripts to ensure congruence between this process and each respondent's comments (Hesse-Biber, 2016; Heigham & Croker, 2009). Reflexivity was also maintained by acknowledging the researchers' background, philosophical approach, and emotional responses during the research (Mauthner & Doucet, 2003). This method was achieved through ongoing self-critique and self-appraisal (Table 4.2) (Gilgun, 2010) related to personal attributes that might have influenced all steps of the research, from developing the proposal, to developing questions, debriefing interviewers, listening to audio interviews, analyzing the data, and writing the results.

Rigor in interpretation (Ratner, 2002) was maintained by treating data in a manner consistent with earlier in-depth studies related to the concept of patients' values, which allowed us to establish the degree of accuracy/objectivity to ensure that the results were based on the rules (Gergon, 2001), and had a strong theoretical and conceptual foundation (Ratner, 2002). To further enhance the credibility and confirmability, all steps of the analysis and preliminary data were communicated regularly and discussed among members of the research team until consensus was achieved (Sundstrom, Busby, & Bobrow, 1997). Furthermore, verbatim quotations were applied to deepen the understanding of the themes and ensure transferability. The interpretation process was also described in an audit trail that revealed the timing and justification involved in making decisions throughout the research process (Olson, & Young Schultz, 2015). We vigorously sought negative cases, which provided us evidence of the complexity of this phenomenon and indicated other possible mechanisms involved in the influence of values on self-care (Morse, 2002). Multiple realities were discovered through two types of questions: value-related questions and experience-related questions. Investigator triangulation was maintained through the involvement of a team in developing questions; interviews were conducted by experienced researchers, and data were analyzed by researchers with varied experience[12].

Table 4.2

Critical Self-Reflective Questions

Questions
• What are my assumptions about patients' values? • What types of bias might I bring to this research? • Can I differentiate between personal perspectives influenced by my own values and attitudes, and my scientific-based views (skills)? • Am I an insider, outsider, or both? Is my position distorting the meanings ascribe to patients' responses? What is the degree of my objectivity? How intimate are my insights into participants' interpretations? • How might age, race, class, gender, nationality, experiences, culture, ancestry, personality, emotion, and language impact my analysis and the interpretation of the data? • How might professional knowledge contribute to revealing the reality implicit in the data?

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[12] See Appendix V for further details about methodology.

Findings

Two overarching themes addressed aspects of values and decision-making: 1) a direct relationship: how values determine self-care decisions, 2) a complex relationship: how HF and it's self-care influence the priorities assigned to values.

A Direct Relationship: How Values are Determinants of Self-Care Decisions

Decisions to both adhere and deviate from self-care recommendations were influenced by patients' values. Two main types of values were perceived to influence this process: functional values and emotional values (Figure 4.1). Selected quotes from the interviews that support these values are presented in Table 4.3 and 4.4.

Functional Values

Functional values involve an action or activity undertaken by patients, health care professionals, family members, or others, and are categorized into three sub-themes: self-related values, other-related values, and health professional-related values. While these three subthemes are common for both adherence decisions and non-adherence decisions, these components are interrelated– that is, they both affect and connect closely to each other (in Figure 4.1, these three sets are separated by a dotted line, which indicates the interplay between their components). For example, in one patient, the desire to be involved in decisions and to be informed as healthcare-professional-related values, contributed to the pursuit of the value of control over the body, which is a self-related value.

"It's an education thing [that is important to the respondent]. When you're armed with education, you're – you're a better person for it" "I asked a lot of questions with regards to medication and symptoms, just to get clarification" "I would like to know where I am at …I need to be in control. I don't like being out of control."

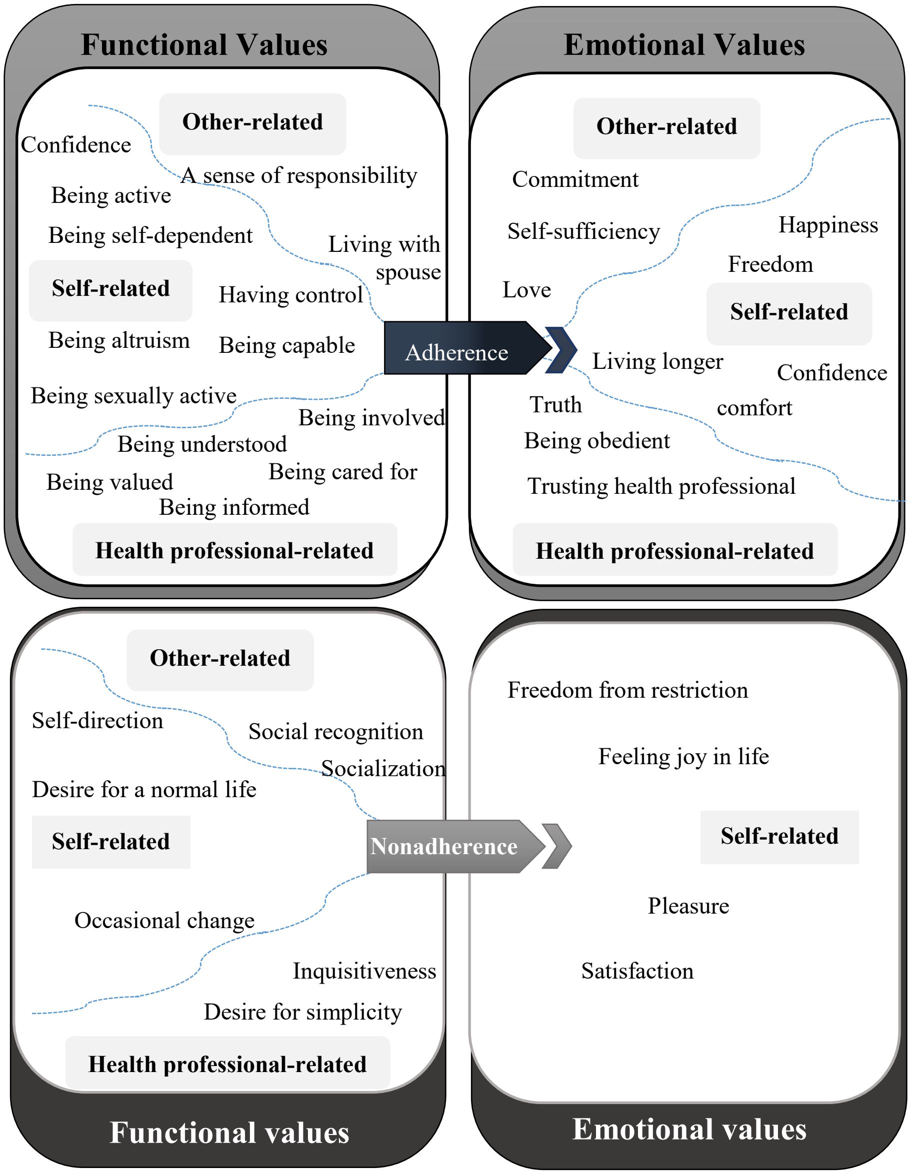

Figure 4.1

Functional and Emotional Values Involved in Self-Care Decisions

Self-related values

Self-related values are related to the patient herself as well as to her capabilities. In the context of HF self-care, self-related values take a special prominence because HF tends to diminish patients' abilities in a range of activities, such as swimming, climbing, traveling, cycling, gardening and working. As such, self-related values were prioritized by all of the participants in this study with the values of being active, being self-dependent, being confident, being capable, having control over life, being altruistic, being sexually active, and/or being able to love a partner viewed as crucial and influential motivators for adherence. For example, two men noted that they were adherent because the pursuit of sexually activity or love was their most important value: "Doctor has got me on enough medication to ensure that [sexual performance ability]." One male confided that his "biggest" and most difficult problem related to dealing with staying sexually active. Adherence to medication, however, allowed him to overcome the issue of experiencing shortness of breath – the main hurdle to maintaining sexual activity. Another patient pointed to the value of loving and feeling loved: "It was because of a girl I lived with 30 years ago. And then I never seen her for 30 years. And then, we started to get back together. That's why I was gonna get healthy." Adherence was also pursued by several patients who were motivated by the desire to regain their physical abilities (as one patient stated: "now I have to stop and take care of this [HF]. Like, I just want to keep going – which is what I was used to.").

In contrast, other self-related values emerging from the narratives contributed to nonadherence. These included the value of desiring a "normal life" and self-direction[13]. For patients for whom the values of self-direction was pivotal, different elements of self-care, such as seeking help from health professionals and using low sodium diet, often conflicted with this value. For example, one male respondent referred to his own strategy of preventing HF exacerbation; when he felt unwell, rather than seeking emergency treatment, he drove toward

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[13] The term "self-direction" as used here is roughly synonymous with "autonomy." We have opted for this alternative form given that "autonomy" is used in some contexts to connote a state of mind; whereas self-direction is related to action.

the hospital parking lot and stayed in his car until he felt comfortable, in spite of the risk. He noted that he did this 100 times, and only went to the ER once:

“If I had a chest pain or whatever you wanna call it chest pain, or indigest – I would start to freak out. I would – but I’d jump in that pickup, go to Emergency entrance. I don’t know how many nights I have spent in an Emergency, but never go in,”

Another respondent stated: “Don’t you tell me what I’m going to do. ‘Because I’ll tell you [doctor] what I’m going to do. And you’re never gonna change my mind. And whether it’s right or wrong, in my mind… you know what I’m saying.”

Health professional-related values

A number of important values concerning patients’ involvement with health-care professionals are closely related to self-care adherence. These include being involved in decisions, being understood, being informed, being cared for, and being valued. One of the patients who explained all of these values descriptively rationalized the importance of pursuing them by stating, “It is my life.” In contrast, the value of inquisitiveness, which is the curiosity-driven examination of anecdotal evidence, weighed against the recommendations of health-care professionals, contributed to nonadherence in one case. The patient’s observation of and comparison between the paradoxical and contradictory results experienced by adherent and nonadherent relatives made him uncertain about the potential results of self-care. Patients’ responses also suggested that a desire for simplicity was another value that often conflicted with self-care adherence. The desire for simplicity was found not to be fulfilled either by health-care professionals in their communication style, which used medical terminology, or via the implementation of self-care instructions, especially diet plans for those with comorbidities, which were challenging.

Other-related values

Other-related values refer to the patients' commitment to significant others, including family members, relatives, friends, and pets. These values, which included family security, a sense of belonging, and a sense of responsibility to others, were seen to contribute to self-care adherence in varying ways. For example, some participants focused on other people, such as their spouse, children, and grandchildren, as being a source of motivation to engage in effective self-care: "I wanna be around to see them grandkids grow up." Conversely, a participant who had lost his beloved wife and had lost his sense of mutual connection with her, was not motivated to any live longer. Adherence to self-care behaviors was lower when patients reported pursuing values associated with socialization ("but if you're with other people, you're moving and travelling around, you know, I don't wanna be the…), social recognition (as one respondent stated: "I would never tell anybody at my work. I didn't wanna be labelled.") and commitment ("Heart failure has been going on. .. I ignored it at work… the fatigue coming home, but totally denying it.") often because the demands of these social situations were perceived to necessitate deviating from diet, alcohol and fluid recommendations.

Emotional Values

Emotional values are those associated with patients' emotions in relation to themselves, health-care professionals, family members, and others. Similar to functional values, these are categorized into three types: self-related values, other-related values, and health professional-related values. These values may be linked to adherence and nonadherence.

Self-related values

Self-related emotional values express patients' ultimate emotional desires. These can serve as motivational factors to promote adherence to self-care behavior; such as living a longer life, happiness, freedom from disease, comfort, and higher life gratification. In contrast, other emotional self-related values contributed to nonadherence. These include: feeling joy in daily life, having freedom from restrictions, or attaining a pleasurable lifestyle.

Healthcare-professionals-related values

Trust and being valued are emotional values that are related to health-care professionals. These values contributed to self-care adherence in several of participants in this study. For example, when a patient explicitly explained that being valued and feeling trust in health professionals resulted when other functional values, including being involved in decisions, being informed, being understood, and being cared were pursued. As a result of this trust, patients successively adhered to self-care regimen. Values can therefore influence self-care adhered in multiple indirect ways.

Other-related values

Self-sufficiency was identified overtly by several participants as a mainly emotionally-based value. It was frequently manifested in the desire not to be a burden to their spouses, family members, or health-care providers. One respondent explicitly stated “ [I] don’t want to be a burden”, “ not a burden on others” .Thus, the value of self-sufficiency motivated self-care adherence as a way to diminish such burdens. It is thus primarily an emotional value that retains aspects of functional values. It is also an other-related value that contributes to self-care adherence. For one male who was suffering from sitting and observing his wife shovelling snow, maintaining health was crucial.

The feeling of being a burden as a result of not being able to pursue the value of self-sufficiency was found when a patient feels partially or fully dependent to others. One male and one female patient stated their preference to termination of their live in case of being totally dependent to others: “If I lose my dependence altogether, then I would be grateful if somebody would just put a bullet in the back of my head”, “[I am] not gonna be a cripple…The assisted dying, I am hundred percent for it”

A Complex Relationship: The Influence of HF and Self-Care on the Priority Assigned to Values

How then did aspects of heart failure influence aspects of patient values? Aside from contextual and individual factors such as acquiring precise, understandable knowledge, and family support, the condition of HF and the way that patients address it through effective self-care, impact the process of prioritizing values. One respondent commented that “the same things [values] [are] […] just as important as before … but not in the same order. Representative quotes illustrating aspects of such influence, as well as patients’ perceptions regarding impeded values, are presented in Table 4.5. Overall, the relationship between aspects of participants’ heart failure and their values was complex and indirect (Figure 4.2).

Change in Priorities Assigned to Values

Most HF patients stated that their values remained constant in terms of perceived importance; however, the priority which was ascribed to these values changed due to the symptoms of HF or behaviors associated with self-care adherence: “I mean, the heart failure in itself, through the medicine, changed the way I would do a day” This patient, who ranked achievement as her most important hierarchical values spent considerable time on creative writing. Although the side effects of medications hindered her mental and physical productivity and made it harder to think and write, her overriding desire for freedom from disease and having a longer life compelled her to reconfigure the hierarchy of her values. Consequently, although the value of achievement was still very important to her, she now prioritized values of longer life and freedom from the disease over her writing. Although the medication interfered with her value of achievement, she continued medication adherence and indicated, “It is small price to sacrifice.” Similarly, two other patients directly stated that they prioritized the value of health primarily only after the HF diagnosis.

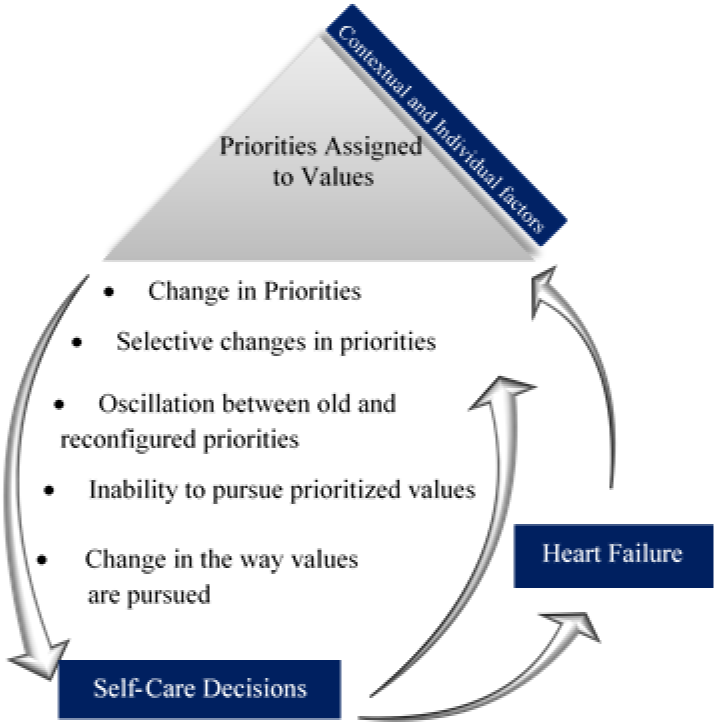

Figure 4.2

The Complexity of the Influence of Values in the Self-Care Decisions

While a significant proportion of patients stated that they shifted the order of their values, contradictory themes were evident within the narratives. The interactive effects of HF and values affected self-care decision differently. That is to say: the reconfiguration of the order of values was selective and, changes in the ways that individual patients prioritized values varied for different self-care decisions. As one participant stated that “I am good at getting the pills ...but some other aspects of it (self-care) is ... there [are] so many things." Accordingly, one male respondent who believed that the order of his values had changed over the course of HF, this was not the case when physicians recommended that he change his diet. Like other patients, he still prioritized the value of pleasure over the value of being healthy by maintaining his regular diet. In addition to pleasure, socialization was another value that was repeatedly raised throughout the narratives and was found to be incompatible with adherence to a low-sodium diet, or abstinence from alcohol. When a patient had social company, or was socializing with friends, he or she could revert to his or her previous priorities, of socializing and pursuing pleasure over being healthy around self-care. The selection of priorities may also vary depending the patients' own assessment of self-care instruction. For instance, two males indicated that they attempted to adjust their intake planning; however, they ended up feeling bored, or simply stated "[I] Don't feel like it, after a while." As the challenge of incorporating adjustments was expressed another one male patient: "You can't just quit [your previous habits]and walk away…it doesn't take long [to revert to her old ways] … it is everyday life." Another female respondent also noted: "Now I don't have motivation [to keep exercising]."

Oscillation between Configured Value Priorities and Reconfigured Value Priorities-Values Can also be in Flux.

An improvement in the severity of symptoms could lead to participants seemingly forgetting the condition and to a trade-off between the previous and reconfigured value priorities, which may also depend on the amount of time during which HF symptoms were previously experienced. For example, two male patients referred to situations of trade-off by indicating that their health was not prioritized unless they had breathing problems. Furthermore, priorities around values in the same participants could vary over time. For example, two male patients acknowledged that their priorities sometimes differed, on "some days"; one female patient used the expression "but occasionally" to express this selective change:

"I can control it. But some days, you know, you have an extra pop, or you have… you know, eat wrong or… and it just throws everything off."

Inability to pursue prioritized values

The pursuit of the prioritized values is in conflict with physical ability. In their accounts patients commonly expressed a sense of failure and futility around values. Some patients, depending on the severity of HF, reported being unable to pursue some of their key values, such as being active, gaining social recognition, achievement, and being responsible. As one patient stated twice during an interview, "Mind says yes; body says no," Almost all HF patients explicitly or implicitly referred to HF and self-care as limits, given the induced incapability to pursue their prioritized values. Other described it as "a sense of loss", "a huge loss", "a death sentence" (a phrase used by two patients), "a life-challenging condition", "a life-altering condition", and " a real changer."

The incompatibility of HF with the pursuit of patients' most important values interfered with their normal lifestyles; thus they predisposed them to experience three types of reactions. The first of these was associated with negative emotions - struggling to cope with a situation by reporting the feeling of frustration, anger, and willingness to die:

"I've always had a lot of energy, so… That would slow me down. I don't like being slowed down. I'm being slowed down right now, and it's making me mad."

The second type of response was associated with low adherence to self-care recommendations due to an choosing not to be adherent and proceeding with living with HF and its limits:

“I learned to live with it…when I get annoyed and go, “oh, to hell with this.” It always – well, I suffer for it. And I know it. But… it doesn’t last long. [Doctor said] you can't do that. Oh, don’t tell me what I can't do.”

The third type of response was about defiance and involved consciously rebelling against heart failure by deliberate means. For example, one female patient drank more water after learning about the necessity of limiting daily fluid intake. Another female participant refused to exercise and became “more angry” when her husband insisted on exercising. Another man expressed:

“The feeling there’s sometimes I get so damned annoyed that I just… I just go ahead and do it. But… and I suffer for it.”

Changes in the Ways in which Values are Pursued.

While some patients complained about their powerlessness to pursue particular values, the response that one highly educated patient provided yielded an alternative perspective. The patient stated that she still pursued the value of pleasure; however, the way that this value was pursued had changed. This was in contrast with other patients, who remained tied to their previous ways of pursuing the value of pleasure (specifically in relation to regular diet), which were incompatible with self-care adherence and led them to be non-adherent.

Table 4.3

Selected Quotes Pertaining to Main Themes (Emotional Values)

Sub themes	Representative quotes
Pleasure of eating	• I like lean meat or anything – well, my favourite – my favourite foods are bread, butter – this thick. And potatoes. • Everything’s got salt in it. It’s just… Ah! And I said another thing ah… be a vegetarian? No way in hell am I gonna be a vegetarian. I just… We had steak tonight for supper.

	• I love vegetables and fruit. There's another thing – downfall is fruit. I'm only supposed to drink two liters of – of liquid. Well, I drink more than that. I mean ah… I eat oranges and – everything … So I know I'm way over two liters. • Things that used to give you pleasure … I would really value. • It would have been really special to me, if somebody had taken me to the Empress for tea. • The dietician, she's a great [girl]. But, "you can't have this, you can't have that." I said, you gonna make me a vegetarian. My wife's a half-assed vegetarian. No. I like a steak, I like a hamburger – not every day. And I said, there is times when I've gone out and just eat what I wanna eat. But I don't do it that often. I don't do it that often. • I've had three chocolates today. Oh, and I am not supposed to have alcohol either and I don't very often.
Trust	• She [the patient] on the way back in from lunch was describing [her therapist] and [her] Doctor again, saying that it was just their ability to um, both be incredibly direct with her, that made her trust them (FN*).
Living longer	• I feel quiet confident that, I am gonna live for a while longer.
Living with spouse	• After she is gone… I don't have the same enthusiasm … I don't really have any fear of death.

*Field note

Table 4.4

Selected Quotes Pertaining to Main Themes (Functional Values)

Sub themes	Representative quotes
Social recognition	• Um, I got the sense throughout the interview that for her, it was important to kind of maintain the appearance of not being too sick. This was kind of extended to work, to her husband, to her kids. Um, but inside, you could tell that it affected her (FN*).
Being informed	• It's an education thing. When you're armed with education, you're – you're a better person for it. Like you know, okay, I'm at this stage. So, what do I need to do? • I asked a lot of questions with regards to medication and symptoms, just to get clarification, but I think I still don't understand. So, I think – I wish I would have probed a little bit more with symptoms. • Especially in a hospital. I know exactly what I'm taking. You know, or ask why I'm taking it if I don't know it.

Self-direction	• You have to. I don't care who it is. You gotta. Somebody get the wrong… let's say a nurse hands over something to somebody, "oh yeah, that's for…" But the wrong dosage – you know, like it's all kinds of diff – everything's that could happen. So, I try and keep right on top of it. Especially in a hospital. I know exactly what I'm taking. You know, or ask why I'm taking it if I don't know it. • I'm not hurting you, I'm hurting me. And I know I'm gonna hurt me, but… like I said, to hell with it. I'm gonna do it anyhow. And I suffer for it. But I'll probably do it again
Inquisitiveness	• One of his uncles who basically smokes and eats the wrong things… he absolutely does everything wrong with regards to self-care and yet he is still alive. • But I know, I have to my water intake, I have to kept down, I guess. I love fruit. I just – I can eat fruit. But they say I'm only supposed to have two liters a day of – I've [had] three – avoid three. But then, that's funny. Cause [Because] yesterday, I don't think… I had any – but my mouth gets dry. That's how come I drink. My mouth gets dry…But they said, other than that, no, just… like I said, it is what it is. • I know, I have to - my water intake, I have to – kept down, I guess. I love fruit … But they say I'm only supposed to have two liters a day of … But then, that's funny. 'Cause yesterday, I don't think… I had any – but my mouth gets dry. That's how come I drink. [Interviewer: Uhum] My mouth gets dry. So it's that I… so they… so… But they said, other than that, no, just… like I said, it is what it is • I just asked a lot of questions. I didn't take anything for granted. Ah, you know, I… So, I just probed and poked and… [chuckling] got what I thought I needed to know.
Being understood	• He (friend) says, "I'm gonna book it all. If you can't go, don't worry about it." … So, I have been really like supporting – supportive friends. Which is – helped a lot.... that's made a big difference.
Feeling ease and understanding the condition (desire to simplicity)	• Um, what's important to me now is that… I have a routine that's established. [Clears throat] And I'm very steadfast about keeping that routine. • I couldn't pass that [information] on, because of some of the terminology…I didn't know
Health	• Everyone says, money… fine. But you need your health. And that is so true.
Being Independent and not being a burden	• This is a participant whose health has been well-monitored and is pretty stable right now… He didn't wanna be a burden. Um, he wants to live independently and so he said if ah, that anything happens, just to let him go, so he's not a burden on others, and he doesn't have to rely on others um, for his needs; which seems to be something very important to him (FN).
Social recognition	• I got the sense throughout the interview that for her, it was important to kind of maintain the appearance of not being too sick. This was kind of extended to work, to her husband, to her kids. Um, but inside, you could tell that it affected her (FN).

Being altruistic	• Values… Yeah, I've become more selfish.
Living a normal life	• I learned to live with it. I mean, I know what I can do and what I can't do. And I respect it. So, I can – if – when I get annoyed and go. • Whether something's happening or not happening, that's positive. That there's always order in everything. I might not see it, I might not feel it – but there is order. And that's what sustained me to a certain extent. • But I never really considered it really serious …nothing has really held me back too much. • I'm happy. I'm satisfied. I said, whatever. Whatever happens, what are you gonna do about it? You know, it's… it's… comme ci, comme ca [so, so], or whatever you wanna say. Yeah, yeah. It is what it is.

* Field note

Table 4.5

Selected Quotes Pertaining to Main Themes (Prioritizing Values and Perceptions due to Inability to Fulfill the Order Assigned to Values

Sub themes	Representative quotes
Values are in flux	• I know what I can eat. Yeah, I just say – some days, I say to hell with it. I don't care. The next day, oh, I'm suffer – I'm not suffering. • My health was not always the number one thing –except when I couldn't breathe.
Conscious rebelling against self-care	• He [husband] tries to push me [to exercise], but it just seems to make me more angry.------ • Um, and then I asked her about a drink of water, and she said that she really has to restrict herself to one and a half liters – and that's why she loves water so much now.
Limits	• You know. And my – except my mind says yes. But the body says no. You can't breathe and you can't move. That pretty much restricts ya [you]. You know. But now that non-breathing part, that's the worst.
Perceptions of frustration	• I know the frustration is partly because I can't do what I want to do, right? I'm – I'm limited, I'm hindered. • It's kind of frustrating because you know you can do something and you can't.

Perceptions of life changes	• It’s life-altering. I was always very active like, hiking and skiing. And I rode my bike everywhere. And now, I – I can’t do that stuff…I can’t physically do it. I run out of wind and everything. And then um, ah, the cold, I can’t take the cold. • It’s a life-changing thing. It’s just… you gotta learn to slow down and… take it a day at a time. • I mean, the heart failure in itself, through the medicine, changed the way I would do a day.

Discussion

This study indicated that HF and self-care cause patients to reconfigure the priorities of their values. In some cases, these may be incompatible with the pursuit of some of the patients’ most important underlying values – preventing them from pursuing these. In addition, for the first time, we identified a typology of values as determinants of self-care decisions in HF patients with NYHA class II and III. Two types of values, functional and emotional, were identified as being involved with both adherent decisions and non-adherent decisions. Both categories of values have been found in non-health related contexts (Lee, Lee, & Choi, 2011; Sweeney & Soutar, 2001). However, while these studies consider social values to be a third type of values, we found that social values are embedded in both functional and emotional values. Thus we categorized each group, functional and emotional values, into three sub-groups: self-related values, other related values, and health professional-related values. While self-related values pertain only to the self, other-related values and health professional-related values are two types of social values (Câmara & Pereira-Guizzo, 2015; Kenter et al., 2015).

In contrast to past studies we did not find a linear link or relationship between individuals’’ values and decisions (Tan et al., 2010) - instead the relationship was indirect and complex (Karimi & Clark, 2016). This disparity may reflect the specific nature of HF, a chronic disease with fluctuating symptoms that requires complex daily self-care decisions, which interfere with normal life (Clark at al., 2014; Pattenden, Roberts, & Lewin, 2007), including the satisfaction of basic needs, such as food, drink, sleep and sex. This was evident in our recent study, which found that HF patients' who failed to pursue their values due to disturbed sleep induced by medication adherence became less adherent (Karimi & Clark, 2016). Indeed, the values related to those basic needs become more pivotal. Thus, when the requirements of self-care behavior influenced patients' failure or success to fulfill those values, their decisions to be adherent or nonadherent were affected.

This study corroborates and extends previous findings that self-care decisions are made based on the patients' prioritized values but are also influenced by the blocking of some values (Karimi & Clark, 2016; Lee, Low & Ng. 2013). However, the priority assigned to such values can be in flux (Heiberg, Finset, Uhlig, & Kvien, 2005). This leads patients to be selectively adherent – that is, patients may adhere to certain self-care recommendations. (Marti et al., 2013). These findings also provide evidence about the mechanisms through which values are blocked (Karimi & Clark, 2016). For example, when patients feel prohibited from a conduct (e.g. excessive fluid intake), and conversely, when some patients are pushed to do an activity (exercising), their value of freedom may be blocked and patients' responses may manifest as conscious rebellion against the recommended behavior (e.g. increased desire to drink water). A recent study also revealed the relation between psychological factors and intense craving to drink water among HF patients (Waldréus, 2016).

The study also addresses important yet long-standing limitations in published literature on HF patients' values. Firstly, values have not been adequately conceptualized in past studies. Second, patients' values tend to be conflated with patients' preferences despite these being conceptually and fundamentally different. Third, patients' values are investigated by looking for "What is important to you now?" "What is your biggest concern right now?" (Allen et al., 2012,

P. 1940). Such queries are overly general and insufficiently focused given that they cover all types of self-care behavior. Rather, patients' values, however, need to be understood in-depth. This can be achieved by considering that patients' values can be related not only to patients but also to other people (e.g. family members, care givers, or friends) as well as to health-care professionals. In addition, different value systems may be involved for different self-care behaviors, such as taking medication, weight monitoring, sodium reduction, and exercising. Therefore, in one patient a specific value such as the value of being healthy can be prioritized and fulfilled for specific self-care behaviors, such as taking medication; however, it may not influence other behavior (e.g. sodium reduction). Such selectivity needs to be identified in clinical practice and incorporated into research.

This failure to capture patients' values precisely, and the lack of an appropriate approach, contribute to our current lack of understanding of patients' non-adherent behavior (Riegel et al., 2012) and past interventions to improve HF self-care (Clark et al., 2009). My findings suggested that a patient-developed approach can be identified based on key information that is embedded in the conversations with patients. The effectiveness of supporting patients as they identify ways to pursue their values should be examined in future research. Further patient-oriented research may also benefit individuals by engaging them in identifying how best their values can be conveyed to nurses, and also by developing patient-centered approaches that to enable us to more effectively support patients and consequently improve outcomes. This important and under-researched area requires attention in order to address the ongoing and still unsolved issue of non-adherence.

Study Limitations

According to the patients' preferences, some interviews were conducted in less private place or situations (for example, in the presence of family members or friends). Such situations may have created some hindrances for people who wished to candidly express some aspects of their values (King & Horrocks, 2010).

Furthermore, it is important to note that, the majority of the participants in the study were male. It is evident in the literature that a number of values are linked with gender (Lyons, Duxbury, & Higgins, 2005) in general and also in the context of chronic disease (Porter,1994). It is thus likely that such results limited the range of responses from females; the types of values that are involved and their function in self-care decision-making among females vary from those of males. Two patients, a male and a female, alluded briefly to *their relationship issues;* they refused to divulge information for various reasons (e.g. privacy). It was therefore impossible to explore this area sufficiently; this is a matter that needs to be taken into account in future research in terms of its importance as well as the appropriate approach that is required to be employed.

Conclusion

Two types of values serve as determinants of self-care decisions. HF and self-care limit patients from pursuing their regular prioritized values. This may cause negative emotional, nonadherent, and rebellious responses against recommended behavior. In the context of HF, patients may also reconfigure the priority assigned to their values. However, adherence to the reconfigured values may be complex. Patients make decisions based on their prioritized values, which may differ for different elements of self-care behavior. A particular prioritized value that directs one element of self-care behavior may not be prioritized for other elements. Thus, prioritizing values for elements of self-care behavior is selective. In light of the findings of this study, patients can be supported by helping them to find alternative ways to pursue their values, which are not fulfilled due to limitations that HF and self-care can present. Patient-oriented research is thus required to provide approaches to asses and support patients’ values.

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Chapter 5: Discussion

The goal of this doctoral thesis has been to examine the concept of the patients' values and to understand how HF patients' values influence their self-care decisions. This chapter will reflect on the results of this thesis with an aim to integrate the thesis in its entirety as follows:

- The first section will present the synthesis of the findings of the three studies in a general framework. It will do so by proposing a model to delineate how patients' values are involved in self-care decision making. Within the model, an antecedent functions as a trigger that contributes to two consecutive levels of mechanisms that affect how individual values are chosen and how they are involved in making self-care decisions. This section also examines my reflection on the model as well as the limitations related to the three studies.
- The second section will review existing gaps and offer some directions for future research. It will consider the implications of those findings for both nursing practice and future research by providing a brief discussion of the application of the CMNS method to analyze qualitative and quantitative data for future mixed-methods systematic review studies. It will conclude with recommendations for practice (See Appendix Y for summary of the results).

Section 1. Synthesis of the Findings

Drawing on the three studies above, I propose a model, called the Value-Driven Self-Care Decision Model (VDSDM) (Figure 5.1). It is constructed based on the main finding of this thesis, which is that values are a main determinant of HF self-care decisions that either lead to adherence or non-adherence to self-care recommendations. The VDSDM is the result of exploration and cumulative learning, an evolutionary process that emerged as I pursued my dissertation research. The exploration began when I proposed a preliminary concept map (Appendix D), based on a literature review, in the primary phase of this dissertation. Next, in addition to clarifying the concept of patients' values – which was foundational for this thesis – through a concept analysis study, I undertook a mixed-methods systematic review that allowed me to propose two models. Those models illustrated the complexity of the function and types of values that are involved in self-care behavior. The breadth and the depth of my understanding were then expanded upon with data from in-depth interviews with HF patients in the focused study. Thus, I proposed a model to depict further mechanisms which underlie the value prioritization process.

Based on all of those micro models, I propose the VDSDM, which combines the mechanisms they illustrate. It is the first model that explicitly unfolds the mechanisms and submachismnes underlying value-based self-care decisions in HF patients. This is novel, as current approaches focusing on self-care decisions either ignore the influence of patients' values, or are inefficient in elaborating such complex phenomena. The theory of value change (Wright, 1983), is a well-cited theory which theorizes adjustment to disability, by proposing four major value changes among people who become disabled (Appendix W). However, this approach is more disability- context- based and fails to explain HF self-care decisions.

This model addresses how HF patients' values are involved in self-care decision making, which may alter the ways in which patients normally prioritize their values. In the VDSDM, two value systems are considered: configured value priorities, which are the priorities that are normally assigned to values, and reconfigured value priorities, which are about changes in priorities that are assigned to values in response to the ways in which that HF and self-care affect patients' value systems. The model, therefore provides an explanation of how patients' values contribute to being adherent or non-adherent. In addition, it reveals the influence of patients' values as a complex phenomenon; for while there is no simple pathway between values and self-care decisions, each component of this model is complex in itself. As shown in Figure 5.1, the process of the value-driven self-care decision model contains three sequential cognitive phases: antecedents, mechanisms, and sub-mechanisms.

Antecedent is defined as the conditions that precede and trigger the occurrence of the values-laden cognitive responses. I define *mechanisms* as explanations for the phenomena that occur after recognition of the interference of an HF condition with the hierarchy of value systems and ultimately direct self-care decisions. Mechanisms are characterized as follows, they:

- arise when the patient is consciously appraising this interference;
- tend not to be visible;
- are complex in nature; and
- are causal sequences for three sub-mechanisms

Likewise, these sub-mechanisms are complex and are:

- more likely to be verbally stated;
- causal sequences leading to outcomes (adherence or non-adherence);
- manifested as more visible via self-care behavior and health outcomes.

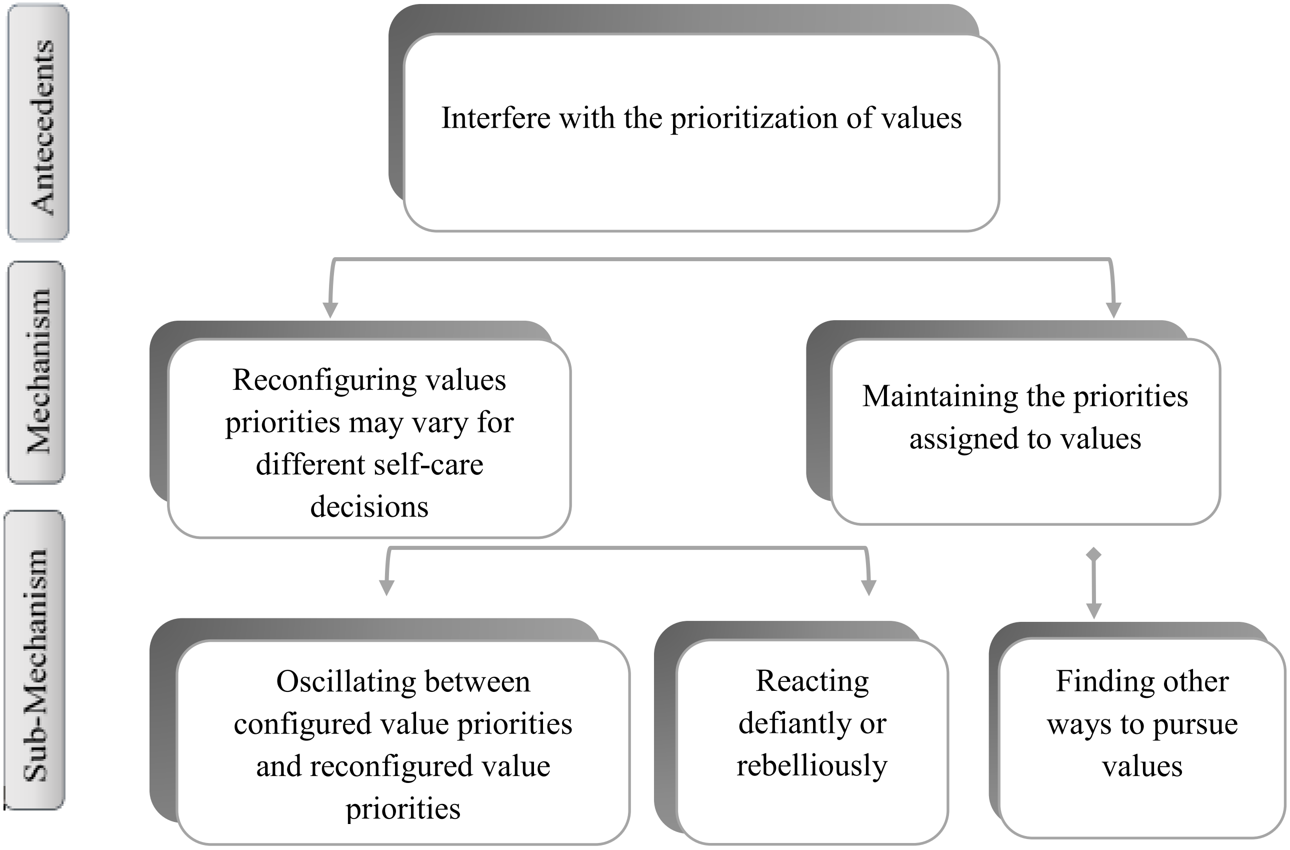

Figure 5.1

Value-Driven Self-Care Decision Model

Antecedents

Antecedents, acting as triggers, involve a dynamic process. People living with HF experience symptoms, practice self-care behaviors, acquire knowledge/experience and experience the outcomes of their action (adherence / nonadherence). Patients thus develop perceptions about the interrelated impacts of HF, self-care, and the pursuit of their values. These perceptions arise from the compatibility or conflicts that are created between patients' values. Cognitive appraisal of this process leads to decisions about how they intend to pursue their prioritized values, and how they deal with the situation that is interfering with the priorities assigned to their values. The importance of compatible and conflicting values and their impact on behavior has been articulated in the literature. This occurs at the individual level (Schwartz, 1996), institutional level (e.g. conflict values between staff members and organizations may cause whistle-blowing) (Singh, 2010), or at the societal level (i.e. compatible values or conflict values between people and politicians may cause reactions with or against politicians [Arzheimer, Evans, & Lewis-Beck, 2017]).

Mechanisms

Perceptions about the interference of a situation with their values, are then transformed into two levels of cognitive mechanisms, as follows:

First-level mechanisms. These immediate mechanisms are categorised into two groups: reconfiguration of values priorities and/or maintaining the priorities assigned to values. These processes are not distinct, and each may be employed for different self-care behaviors. Patients may even navigate back and forth between them, depending on the situation.

1. ***Reconfiguration of value priorities***. The complex process of reconfiguring value priorities usually occurs at the price of changing prior values over the course of HF. These changes in the context of illness have been described as “new paths” (Proot &Yorke, 2013), “adaptive changes” (Bishop, 2005, p. 222) and “shift[s] within the hierarchies of the value system” (Marinelli & Orto, 1999, p. 148). The transition from configured value priorities to reconfigured value priorities occurs mainly because HF is a life-threatening situation, or because patients face limitations in pursuing some of their values when HF is experienced. Such affected values in the context of disability are described as “inappropriate or unattainable” to any further extent (Marinelli & Orto, 1999, p. 149). Therefore, in order to cope with the situation, patients endeavour to make a transition in their hierarchical system. In other words, values that are related to mobility such as competence, physical activity, and attractiveness are demoted in the

hierarchical system (Marinelli & Orto, 1999). This phenomenon has also been discussed by Diamond (2008) in the wider context of society, in which core values are reappraised when a crisis occurs. Comparing the findings of this study with Diamond's insights reveals similarities between the causes of change. While a social crisis is a situation in which varying changes in the core values of a society may occur, on an individual level, HF serves as the crisis that causes a rearrangement in patients'core values.

This process involves not only reconfiguring value priorities in a new hierarchal format, but also introduces new values that were not prominent or were even improbable when this lifelong, progressive, and disabling condition was absent. Pattenden et al. (2007), for example, reported that HF provides a new opportunity to pursue the value of a varied life (which was not previously desired) due to variations in certain facets of patients' lives (Proot & Yorke, 2013). This mechanism has also been described as a way to contend with living through chronic and life threatening disease (Proot and Yorke (2013). Viktor Frankl (1992), a psychiatrist and the author of the book *Men's Search for Meaning*, brought to light the process by which particular values may arise. He offered the anecdote of one patient who was in the midst of end-stage life. In her case a sense of spiritual accomplishment (which was a functional and a context-raised value) becomes dominant, which led to a sense of awe (as an emotional and a context-raised value):

> This young woman knew that she would die in the next few days. But when I talked to her she was cheerful in spite of this knowledge. "I am grateful that fate has hit me so hard," she told me. "In my former life I was spoiled and did not take spiritual accomplishments seriously." Pointing through the window of the hut, she said, "This tree here is the only friend I have in my loneliness." Through that window she could see just one branch of a chestnut tree, and on the branch were two blossoms. "I often talk to this

> tree," she said to me. I was startled and didn't quite know how to take her words. Was she delirious? Did she have occasional hallucinations? Anxiously I asked her if the tree replied. "Yes." What did it say to her? She answered, "It said to me, 'I am here—I am here—I am life, eternal life.' "(p. 77-78)

Although patients may choose to pursue and embrace the reconfigured value priorities, this adopted transition may not be favourable. This state of mind is inconsistent with the claims of Altamirano-Bustamante et al. (2013), who define values for the practice of values-based medicine as “favorable dispositions towards aims that are sought” (p. 2). This might explain why some patients intend to embrace their previously configured value priorities.

2. ***Maintaining the priorities assigned to values.*** Although the reconfiguration of value priorities may contribute to self-care adherence and better outcomes, some patients tend not to make this transition and choose to maintain their previously configured value priorities – which may contribute to self-care non-adherence and poor outcomes. This mechanism may contribute to patients attending to all or some domains of their self-care decisions. Patients tend to maintain their regular values when self-care decisions are incompatible with them, in particular when those values are related to their basic human needs, such as the need for food. Given that both HF (which is normally perceived as being “life changing” [Rodriguez, Appelt, Switzer, Sonel & Arnold, 2008]) and self-care may influence aspects of patients’ lives, including the consumption of food and drink, socialization, being physically active, working, and having sex, patients may tend to retain their configured values. The related values may be pursued through adherence or nonadherence to self-care recommendations.

Submechanisms

The next level of mechanisms, which characterizing some ways in which patients may respond to those larger choices may be as follows:

1. Oscillation between configured value priorities and reconfigured value priorities. Although configured value priorities and reconfiguered valued priorities are two different structures that patients may choose to pursue, oscillation between them is a way that participants may deal with the complexities of decision-making in different situations. Such shifts reveal that values can also be in flux. In other words, the extent to which participants adhere to the reconfigured values differs among them. The pursuit of the joy of eating has also been shown in the literature to be related to such oscillation, which is described in terms of different themes, such as "modifiable determinants" (Greaves et al., 2016) or "intrinsic motivation" (Cossette, Belaid, Heppell, Mailhot, & Guertin, 2016).

Thus, changeability of the prioritized values is not generalizable because some patients still desire to pursue their previously prioritized values to some extent. In addition, the complexity of this oscillation between prioritized values may explain why exploring patients' values through asking the question of "what is important to you now?" is not itself sufficient to fully understand the variety of possible responses (Allen et al., 2012, p. 1940).

2. Reacting defiantly or rebelliously. The effects of HF and self-care recommendations in blocking the pursuit of some values may lead to defiance and rebellious responses. Such reactions are manifested as an increasing desire (or craving) to pursue the blocked values – which are derived from either: reconfigured value priorities or previous value priorities that have been maintained. These values are normally related to the basic human needs, which are natural reinforcers (e.g. food and sex) (Morris, Na & Johnson, 2008). Among foods, salt, fats, carbohydrates, and chocolate are considered extremely palatable (Morris, Na & Johnson, 2008) and are connected to pursuing the value of pleasure (Goodman, 2008). As several studies have shown, once patients are instructed to follow a limited sodium diet, their craving for saltier foods escalates (Bennett et al., 2005; Bentley et al., 2005; Boren, 2001; de Souza et al., 2012; Scotto, 2003). Such an impact on the value of pleasure has a physiological function (Moris et al., 2008). This mechanism has been found to function in relation to four aspects of self-care: low sodium diet, limited fluid intake, increased activity, and hospitalization after symptoms worsen (de Souza et al., 2012; Scotto, 2003). This tendency may be generalizable for similar limitations in other contexts, as in patients with diabetes desperately craving sweets after diagnosis. Therefore, if this mechanism underlies self-care decisions, nonadherence is likely to occur. Thus, acknowledging this mechanism might provide greater insight into developing and employing strategic support for patients.

3. Finding other ways to pursue values. Retaining some of the configured value priorities may lead patients to be nonadherent. However, finding alternative ways to pursue the values that are influenced by HF may be compatible with self-care adherence. The fact that patients can retain the ability to pursue their previous prioritized values was explicitly evident in the focused study, as two female patients used this approach to cope with *outlying* values in order to improve HF outcomes. In this case, two main phases were apparent. First, the participants were mindful of their prioritized values and second, they developed a strategy to cope with the situation that prevented them from pursuing their prioritized values. This could be a basis for future research seeking to examine and develop effective interventions. Chiong (2013) and Charles and Gafni (2014) also placed emphasis on the lack of effective approaches, as well as the importance of developing pragmatic approaches to enable patients to pursue their values.

Overall, this model provides a way of addressing the main research question above: patients make self-care decisions based on whether they pursue their reconfigured or configured value priorities or alternate between them. Patients may then respond in three different ways in a nonlinear and potentially dynamic pattern, depending on circumstances and situations.

Reflection on the VDSDM

The VDSDM model, articulates how values – which are core, abstract, and entirely subjective, and whose priority depends entirely on context – function in decision-making in conjunction with non-cognitive/non-rational processes. Helping us to assess patients' values as coping mechanisms, the model provides avenues and directions to understand how these value, are involved in self-care decisions in a nonlinear and multifaceted way. Such comprehension can facilitate understanding patients' self-care decisions. While commonly used mid-range value expectancy models (TRA, TPB, CSM, and HBM) are based on rational, conscious choices, and cognitive processes, these are insufficient to explain why despite education and knowledge, people vary in their choices. The VDSDM elaborates more differentiated explanations for patients' self-care decisions in four ways.

First, the model mainly focusses on the higher level of determinants, patients' values, which are located in the center of an individual's value system. This is an area that is overlooked in value expectancy models, which focus on attitudes and beliefs. The TRA model, for example, uses patient's attitudes in order to predict behaviour. However, this model does not explain irrational decisions, such as tending to be non-adherent while having a positive attitude toward self-care recommendations, exhibiting craving behaviours, showing habitual responses, and behaving inconsistently in different situations. The VDSDM, however, can conceptualizes such irrational choices by acknowledging that patients' values, in contrast to attitudes, are located in the center of the belief systems and that values prioritized in a given situation lead individual in their decision-making process. This distinction is crucial because beliefs and attitudes can be proxy measures for values, but they differ from values. Measurement of values are challenging, as they are entirely abstract and are not consciously available. Therefore, the structure of this model brings to light a number of key questions in the context of nursing practice, such as: What questions can nurses use to capture patients' values? How can they identify which values are in operation and how they are prioritized? How willing/able are patients to find alternate ways to achieve them? How can nurses help patients to find alternative ways to pursue their values – for example, by occasionally adjusting the dosage of diuretic medication in order to enjoy certain kinds of foods?

The VDSDM also reveals avenues to explore the function of values, and to identify the mechanisms underlying value-laden decisions by grounding analysis on patients' experience. In contrast to the models in which patients' experience are overlooked, this new model benefits from experiences via backward tracking the self-care decisions that have already been made. Such backward tracing is a practical approach to understanding what types of values are prioritized by the patient and how those values function in the process of deciding about a particular self-care element in a given situation.

Finally, although this model appears to focus mainly on patients' values, it is in fact sensitive to the contextual factors that are often disregarded in other models. The contextual factors in the VDSDM model are twofold: dispositional factors and situational factors. *Dispositional factors* are individual-related contexts pertaining to acquired characteristic factors (e.g. experiencing HF) and behavioral factors (e.g. daily self-care behaviours). These types of contextual factors are the main stimuli that interfere with normal ways of prioritizing values.

Situational factors, however, are related to certain external situations that influence the ways that patients prioritize their values (such as socialization, participating in specific events, or gaining new knowledge). One of the reasons that this model appears nonlinear and multifaceted, offering the possibility of alternation between various avenues, is the influence of all of those factors. Thus, this model is basically individual and contextual responsive.

This model can contribute to refining the existing models that are related to decision making and behaviour in several ways, including the following:

1. Focusing on the holistic process of making decisions rather than focusing strictly on logical and cognitive processes.
2. Being sensitive to the integral roles of the individuals' values, rather than overlooking or considering them to be less important elements.
3. Refining the models to be more applicable in practice and provide explanation for wide-ranging behaviours.
4. Refining the models so that they can explain the navigation between two opposing behaviours.

Section 2. Challenges and Implications

Each of the three studies within this dissertation carries its own particular limitations, as each used different methods of data collection and analysis.

I encountered one important challenge when analysing data within both the systematic review and the focused study. This limitation was related to the difficulty some patients faced in communicating certain values. Scholars who have focused on this challenge have noted that understanding values may not be an easy task (Childress, 1970; Hug, 2000; Charles & Gafni, 2014). Values comprise people's psychological worlds and are communicated explicitly or implicitly through literal and metaphorical languages (Dicken & Edwards, 2001). However, social constructionists argue that language is not simply a mirror of thought (Coulter, Myers, & Varacalli, 2007). When values are expressed in language, they may be explicit or only alluded to, in which case they are called relatively unsayable (Redner, 1986; Schick Macaroff, 2013). The notion that patients' values are not often disclosed straightforwardly suggests that values are intertwined with notions of the unsayable, unsaid, ineffable, and unspeakable – which generally refer to experiences and feelings that cannot be expressed through language (Schick Macaroff, 2013).

Bosek and Savage (2007) also remind us of the challenges of expressing values, noting that some important values may be unexpressed as a result of, for example, the fear of being judged and shyness (Curtis et al., 2001; Loughlin, 2014). This thesis also adds to the literature by expanding our understanding of the barriers in communicating values due to, privacy-related concerns. In the future, these limitations may be remediated by including other complementary methods, such as interviewing with dyads in relation to patients' values and using visual methods (e.g. photo diaries, photo elicitation, art and drawing) as well as audio methods (audio diaries).

The Concept Analysis: Key Limitations

Although the concept analysis study achieved its purposes, there were some limitations. First of all, the possibility of overlooking related articles was inevitable in spite of consultation with a librarian in order to ensure an efficient research strategy that effectively captured relevant literature. This limitation aroused because a countless number of studies used the term *value* in alternate ways: applying it within the phrase *p values,* or as a verb meaning to appreciate/evaluate, or as a noun referring to worth. Second, this study was limited to English literature and was largely based on western perspectives, which may limit cross-cultural insights into this concept. This is notable, given that *values* is an ancient concept, which from the time of Plato and Aristotle (fourth century BCE), philosophers from all over the world have explored; hence there are relevant sources available in other languages not accessed in the thesis. Such a broad range of sources may also contribute to knowledge development and expand the concept of values in the discipline of nursing. Third, this concept analysis, in Risjord's terms, was a theoretical analysis, as it aimed to represent concepts as they appear in particular scientific literature (Risjord, 2009, p. 688-9). This study, however, would have benefited by employing a mixed concept analysis method. Such approach would combine a theoretical concept analysis (via literature) with a colloquial concept analysis, which aims to present evidence in relation to "what people say and do" around a given concept, using formal interviews, participant observation, casual speech, or imaginative literature. The fact that such an analysis was not the focus of this study may limit the extent to which our findings are applicable to the practice of nursing, in particular to value clarification and value elicitation techniques.

The Systematic Review: Key Limitations

The systematic review study was also not without limitations. First, this study was primarily limited to English-language, peer-reviewed journals or dissertations published from the year 2000 and onwards. Inclusion of research prior to 2000, and non- English language sources, would have broadened the analysis. Second**,** the lack of prior research studies that explicitly examined patients' values was an unavoidable limitation. Given the identification of only five studies that explicitly addressed HF patients' values, extraction of data in the rest of studies was thus based on conceptual clarification. Third, qualitizing the data (i.e. converting the quantitative data to qualitative data) another part of the CMNS method, provided limited context and depth for these insights (Sandelowski, 2001). In addition, the findings are also constrained given that the majority of the studies included were conducted in high-income countries.

The Focused Study: Key Limitations

The focused study was also subject to several methodological limitations. First, there was an issue with regard to the interview settings. Although all interviews were conducted in a place based on the interviewee's choice, some of the interviews took place in situations (for example, involving the presence of other family members or a friend) where there was a likelihood of invasion of privacy of the participants. Although patients chose the setting, such situations may have created some obstacles for this study, given that when people specifically intend to express their values, they require confidentiality (King & Horrocks, 2010).

Second, the sample size may also be considered as another limitation for the IPA study. Smith et al. (2009) note that small participant numbers in IPA studies are particularly valuable, as they allow for a greater breadth and depth of analysis. This breadth and depth are partly due to the researchers' need to go beyond participants' interpretations. The process of interpretation that takes place on a higher level of order might be hindered with a larger sample. Third, unequal representation of males and females in the focused study is also seen as a limitation (Porter, 1994); the majority of the participants in this focused study were male (67%). Consistent with this view, in the systematic review study, I also found the influence of particular values in the way in which males and females make their decisions. It is thus likely that such results are characterized by limits in the range of responses from males – the types of values that are involved and their function in self-care decision making among males vary from those of females.

Fourth, given that this study adopted convenience sampling, the findings are limited with respect to their population generalizability but open to theoretical generalizability. Finally, critique and limitation in relation to the application of IPA is influenced by the researcher's perspective. Some may argue that this approach is a double hermeneutic approach and lacks guidelines to incorporate the researcher's reflexive impressions and thoughts into the research process. Aside from applying self- reflexivity as an ethical instrument to develop scientific knowledge, this concern can be addressed and justified theoretically within an epistemological view; although ontologically the existence of values is subjective, knowledge gained in relation to HF patients' values was not solely subjective in an *epistemic* sense. Critical perspective toward the objectives of this study was shaped by analysing the concepts of values examined in an immense amount of literature (121 articles were consulted). The systematic review, in addition, provided new insights related to the concept of values. Both preliminary studies made contributions to my scientific-based perspective.

Implications for Nursing

The findings of this study offer implications and suggestions for nursing practice, which is required to provide consistent, comprehensive, and client-centered care to patients. These implications are fourfold.

1. Understanding the concept of patients' values, knowing how values function, and differentiating them in language. The primary purpose of this study is to help to focus nurses' attention on the understanding of three interrelated elements: the concept of patients' values, the types of values among patients with HF, and the functions of HF patients' values. Understanding the importance of patients' values in their heath related decisions, a key element in all human decision-making, is essential, but it has been commonly overlooked. Focusing on an informed way on values may allow nurses and other health-care professionals to avoid using other decisively simple terms and concepts, such as preferences when assessing them and when providing patient-centered care. This may allow us to take into account their core beliefs more insightfully. Such understanding empowers and guides researchers and nurses in understanding individuals' values, and in understanding how this factor, along with other individual and contextual factors, is involved in self-care decision-making among patients with HF. This appreciation can be facilitated via the application of the models, which were developed in the systematic review.

In terms of research, the application of the definition of the concept may allow us to come to a shared understanding with our readers about what we mean by *values* and may prevent some ambiguities from arising due to the lack of a definition. Research, guidelines, textbooks, and practice are not isolated, but interrelated. Consequently, the implications of this study for the literature may be further echoed in practice. In essence, the majority of nursing diagnoses approach patients' values through values clarification or values elicitation exercises that are used as a common intervention. However, nebulousness is evident in clarifying patients' value within those approaches. The benefits of nursing care plans based on such exercise may be compromised. As such, this study may contribute to filling the gap and addressing this problematic situation.

In addition, the concept analysis identified alternative terms that are used interchangeably in the literature and can facilitate the process of searching for future related studies in the review of the literature (see Bakes et al., 2012; Buck, Akbar, Zhang, & Bettger, 2013). Thus, the results of the concept analysis will benefit researchers who are seeking literature related to patients' values. Acknowledging the surrogate terms or alternative terms that express the concept of *values* will allow them to expand their list of key terms, thus increasing the sensitivity of their search strategies in identifying the relevant studies (Buck, Akbar, Zhang, & Bettger, 2013). Understanding attributes (the characteristics of the concept) can also help researchers to extract data pertaining to patients' values, even if the author has applied substitute terms. For instance, a study may focus only on beliefs, but data regarding values may thus be hidden in the text and may be extractable based on the knowledge acquired from the concept analysis (Morris, 1994, Neuendorf, 2002, Tsirogianni, & Sammut, 2013, Schwartz, 1992).

The systematic review study also helps readers to access this evidence-based research. It is impractical for an individual reader to review all of the relevant studies, which often apply to different terms and may fail to provide a care clear definition of the applied concept. This presents a significant challenge for the reader hoping to understand and distinguish between them. Given that our findings aggregated and synthesized a large number of related studies, we have offered greater access to this material for readers. This is particularly important given that readers may not be in a position to evaluate the quality and applicability of an individual study (Paterson et al., 2001); in this review, only qualified studies were included. This strengthens the inferences (outcomes) of the review and increases the validity of the findings.

2. Communicating effectively. Acknowledging the concept of patients' values and its components in particular attributes of patients' values improves our ability and equips us to understand patients' values, inasmuch as such values reside both implicitly and explicitly in language, and in some cases may be uncovered only if the concept of patients' values is understood. Given that values are conveyed both explicitly and implicitly through narratives, active listening serves as a critical component of this communication (Coleman, 2001, Stawnychy et al., 2014). I recommend such practices, which are crucial in understanding how values are involved in nonadherent and adherent decisions. For this purpose, double listening to patients is required in order to understand their values both in their own language and behind that language. Such understanding allows nurses to fulfill their responsibilities ethically and to support patients who become non-adherent.

Another implication of active listening relates to the fact that discussions about patients' values may involve some challenges. Patients are not always confident in discussing their prioritized values. As noted earlier, this was evident in two participants' statements in the IPA study; they explicitly stated their unwillingness to disclose their experience in relation to their intimate relationships because of privacy concerns. Hence, effective communication in a private atmosphere is another important key in uncovering patients' values. Particular forms of communication are required for nurses to gain an in-depth understanding. More research on this subject is required.

Nurses and health-care professionals may also enhance their communication strategies based on the findings of this study in a way that helps them to support patients effectively, individually, and situationally. For instance, the use of key terms such as *someday* or *occasionally* by patients can lead us to explore occasional nonadherence and the situations in which it occurs, as well as how particular values are related to those decisions. This may facilitate effective support in delivering patient-centered care, and in supporting patients in pursuing their values through self-care decisions.

3. Developing effective care plans. The findings of this study allow us to support HF patients in their decision-making process, and may subsequently enhance patients' autonomy. Moreover, this knowledge may also equip us to help patients to identify their prioritized values and to deal with the conflicts that may arise between their values and self-care recommendations.

The knowledge of what values patients are likely to hold when they are adherent or non-adherent to self-care recommendations and how these values contribute to the process of self-care decision-making has offered new insights that benefit researchers and health care professional practitioners, as well as students, seeking to facilitate the achievement of self-care goals, by incorporating patients' values into care plans through patient engagement. Health care professionals should consider engaging patients in care plan discussions, in order to elicit their prioritized values and the influence of these values on self-care decision-making and to convey information on care provision that is consistent with their values (Boren, 2001; Clark et al., 2014). This understanding is important because, as this study has revealed, a certain value may direct patients' decision-making in different ways, and may contribute either to adherence or to non-adherence. This approach would also involve both parties (patients and health-care professionals). Being aware of their values may help patients to engage more with self- care. When patients' prioritized values are in conflict with self-care recommendations, patients' support is critical in order to find alternatives that allow them to pursue their prioritized values, while they remain motivated to adhere.

4. Creating patient-centered educational programs. In light of the findings of this thesis, there are implications for health-care educational programs (Whitfield et al., 2012). We found that patients' values are determinant of all domains of self-care decisions. As such, these values must be integral to the work of nurses in supporting not only patients' everyday self-care decisions, but also their decisions related to opportunities for learning about self-care, which may range from seeking to participate in knowledge development programs to engaging in active learning process (Evangelist et al. 2001; Scotto, 2005). Understanding patients' values in this way may facilitate supporting their decisions individually. The importance of comprehending learners' values in this way has been explored in the literature on *adult learning* (Whitfield et al., 2012). Knowles (1990) notes that "adults filter learning through their value systems" (p. 20). In physiological terms, this process involves the limbic system, which controls an individual's value system and determines how the brain responds to information. Traditionally, adults have been portrayed as selective, self-directed, independent/dependent (Knowles 1980), and participatory learners, in terms of proficiency gains and knowledge development (Boshier 2006). Such attributes however are not generalizable but are clearly related to learners' values. Thus, elicitation of patients' values must be an integral step before proceeding with a patient-centered educational and behavioral self-care program.

Thus, in order to provide more comprehensive health care, integration of patient' values in all domains of care is essential. Acknowledging the meaning of the concept, the central role of patients' values in all types of health-related decisions, the nature of their functions, and the mechanisms underlying their influence are requirements in order to assess and collaborate with patients in developing real person-centred care and effective care plans. Considering that gender may affect the types of values and the function of values that are involved in self-care decisions.

Priorities for Future Research

A number of additional avenues for further investigation have been highlighted by the three studies undertaken for this thesis. The purpose of this section is therefore to discuss the unresolved questions that might be clarified in future research.

In the systematic review study, for example, I found only five studies (for the period of 2000-2014) in which scholars explicitly discussed HF patients' values in relation to self-care behavior (Clark et al., 2009, Cortis and Williams, 2007, Hicks and Holm, 2003, Hodges, 2009 and Scotto, 2003). Research is thus warranted to synthesize the literature within a broader time frame, in order to gather more explicit data. Further studies, both qualitative and quantitative, are also required to explicitly examine patients' values and their impacts on self-care decision-making. More specifically, future research should examine the mechanisms that are proposed in this thesis, and also should explore other ways that value systems may function. It is likely that other mechanisms underlie the manner in which values are involved in self-care decision making. Likewise, the models and mechanisms need to be examined not only in the context of HF, but also in the context of other chronic diseases. This examination may contribute to the development of comprehensive insights toward value-laden self-care decisions in patients with chronic disease.

It is likewise important for future researchers to better understand and characterize patients' values. This study found that those values may be categorized into two main groups: self-related and other-related values. Understanding these distinctions is crucial for the development of more effective and supportive approaches for different patients taking into account different values that underlie their self-care decisions. There is likewise a need first to bring together all existing instruments measuring patients' values. Further research, then, is required to provide efficient, comprehensive and proficient assessment tools to incorporate patients' values into care: both by ascertaining these values, and by understanding and supporting their value-laden self-care decisions (Goodman, Firouzi, Banya, Lau-Walker, & Cowie, 2013; Cottrell, Denaro, & Emmerton, 2013; Wingham, Harding, Britten, & Dalal, 2013).

Regarding alternative ways to explore patients' values underlying their self-care decisions, it is important to examine integrating family care-givers' assessments of patients' values into patients' assessments in order to clarify and identify these values (Clark et al., 2014, p. 95). The insights of family members may be complementary to the patients' contributions, given that they are likely to be aware of patients' values. This proposition, however, must be tempered in light of other experimental results, such as the possibility that HF may impact some patients' cognitive status. It would also be interesting to compare the findings from patients with findings from family caregivers in relation to patients' values. This might reveal their influence on self-care decision making and illustrate how caregivers' perceptions may differ from HF patients' perceptions. Further research is also needed to examine how other approaches such as visual methods and audio methods can facilitate understanding of patients' values. Another area with a shortage of literature is research that explores how effectively patients' values can be communicated with health-care professionals. This area of inquiry should also be extended to investigate what type of skills nurses need to acquire in order to equip themselves to ascertain patients' values.

In this dissertation, exploring alternative ways to pursue prioritized values was found to be a method of enhancing self-care adherence and patients' satisfaction. Although it was developed by patients, this could be considered as a goal and as one intervention for nursing care plans. Therefore, I recommend further research to examine this strategy and to develop alternative strategies to support patients in pursuing their values that are affected by HF and self-care in order to move toward improved self-care/adherence. Likewise, inquiry into how gender differences influence value-laden self-care decisions would be a significant addition to the discipline's body of literature. It would also useful to conduct a longitudinal research to identify and examine the influence of patients' values on their self-care decisions as HF progress into advanced stages.

Implications for Research Method

This study contributes to method development by developing, applying, and examining a novel type of knowledge synthesis in a mixed-methods SR study. As was noted in the systematic review, we call this approach critical meta-narrative synthesis (CMNS). The application of CMNS provided me with insights during the research that were addressed in a publication in which we disseminated this method. The appropriateness of this approach is discussed in the Appendix X.

Conclusion

Poor self-care, resulting in undesirable health outcomes remains as a major concern because its negative outcomes influence patients, family, and health-care system. The influence of patients' values may be crucial in self-care decision-making among patients living with this life-threatening syndrome. The aims of this study were to explore the concept of patients' values and to understand how those values influence patients' self-care decisions. I clarified the concept of patients' values as core beliefs, which are abstract and significant to individuals and whose priority is changeable under certain circumstances. This study contributed a number of insights. First, the attributes and functions of patients' values are specific to the context of HF. This is because values are central to the ways in which HF patients make self-care decisions, which follow a circular pattern. This process is context-based for each of the dimensions of self-care and is based on a prioritized value derived from a hierarchy of values. Values, both in their functional and emotional forms, influence both adherent and non-adherent self-care decisions. They both influence and are influenced by self-care and the severity of HF symptoms. New values, moreover may arise in the context of HF. Values extend to those relating to the self, others and health professionals within a range of personal, life, and social dimensions. Values cannot be assumed to be fixed, normative or similar to those held by nurses and other health professionals.

Based in these insights, I identified gaps and areas for further research. These include understanding the vectors of values in the context of care, and the functions of values, and providing efficient and comprehensive assessment tools to incorporate patients’ values into care. The results of this study should focus nurses’ attention on understanding the concept of patients’ values, the types of HF patients’ values, and the functions of HF patients’ values. Understanding the importance of such values, which maybe implicit or explicit in patients’ language, is a key element in order to help them to adhere to value-centered care, and to support HF patients in their self-care decisions.

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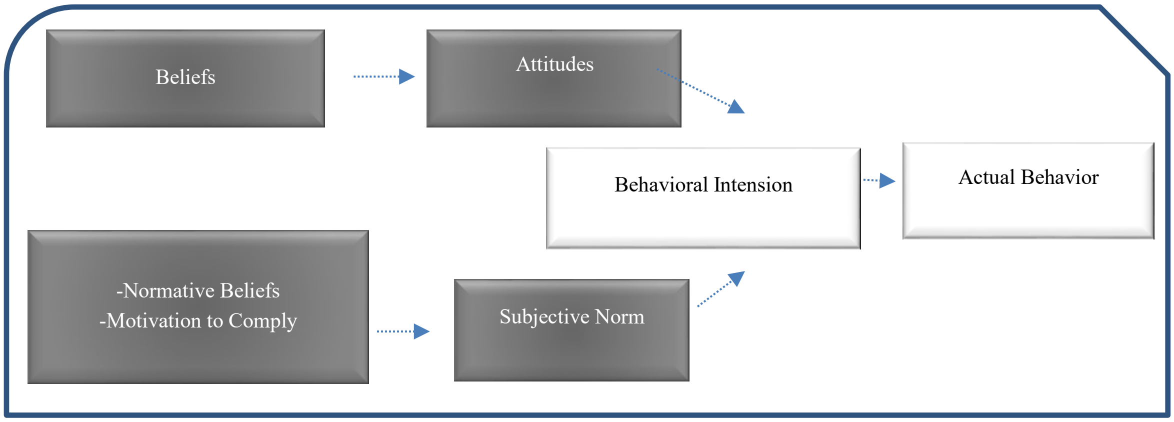
Appendix A: Common Applied Models in Studies of Self-Care

Figure A.1

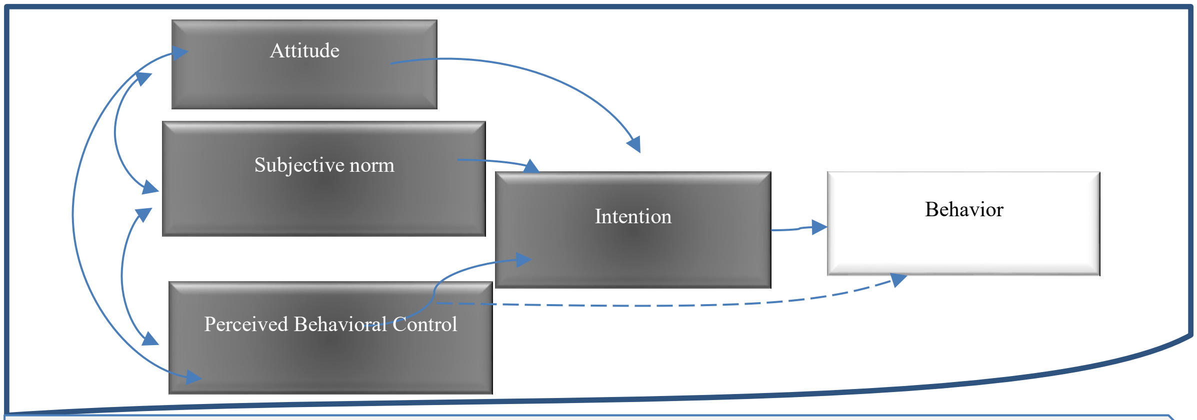
Theory of Reasoned Action. Adapted from *Belief, attitude, intention and behavior: An introduction to theory and research* (1975) by M. Fishbein and I. Aize. MA: Addision-Wasely.



Note. Attitudes and norms are the keys that influence on intention and thereby behavior. **Attitudes** toward a specific behavior are influenced by two connected factors: An individual's beliefs about the outcome of the behavior and evaluation of outcome (whether it is good or bad). **Subjective norms** are influenced by our perceptions of others beliefs (e.g. parents, friends, doctors, etc.) If they have a positive belief about performing the behavior, the positive subjective norm is expected which motivate the individual to comply the behavior.

Figure A.2

Theory of Planned Behavior. Reprinted from The Theory of Planned Behavior by I. Ajsen, 1991. *Organisational Behavior and Human Decision Processes*, Vol. 50. p. 182.



Note. Behavioral beliefs: Beliefs related to a behavior.
Attitude toward a behavior: The degree to which performance of the behavior is positively or negatively valued".
Subjective norm: An individual's own perception of the social pressure that causes to perform or not perform a particular behavior.
Perceived behavioral control: An individual's perceptions in regard to her/his ability to enact a particular behavior.
Intension: an individual's willingness to perform a particular behavior

Figure A.3

Common Sense Model (CSM). Common Sense Model (CSM). Adapted from Behavioral theories and the problem of adherence (1987) by H. Leventhal and L. Cameron. Patient Educ Couns. 10, P. 127.

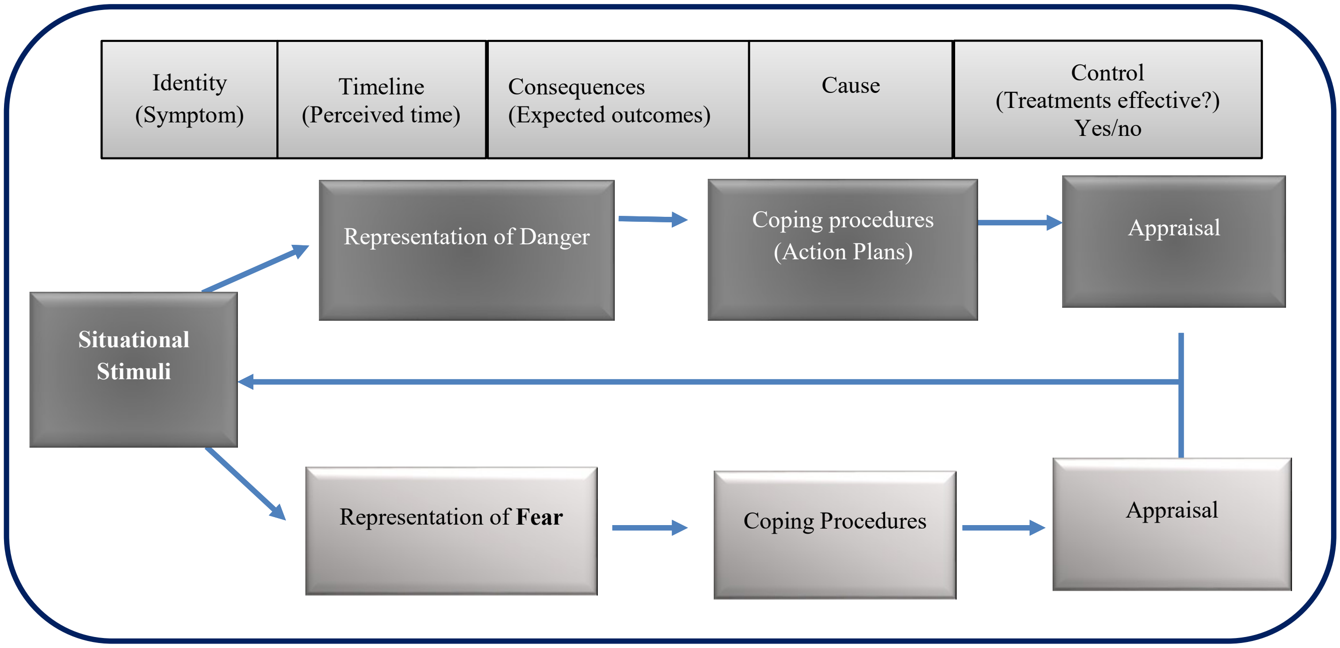
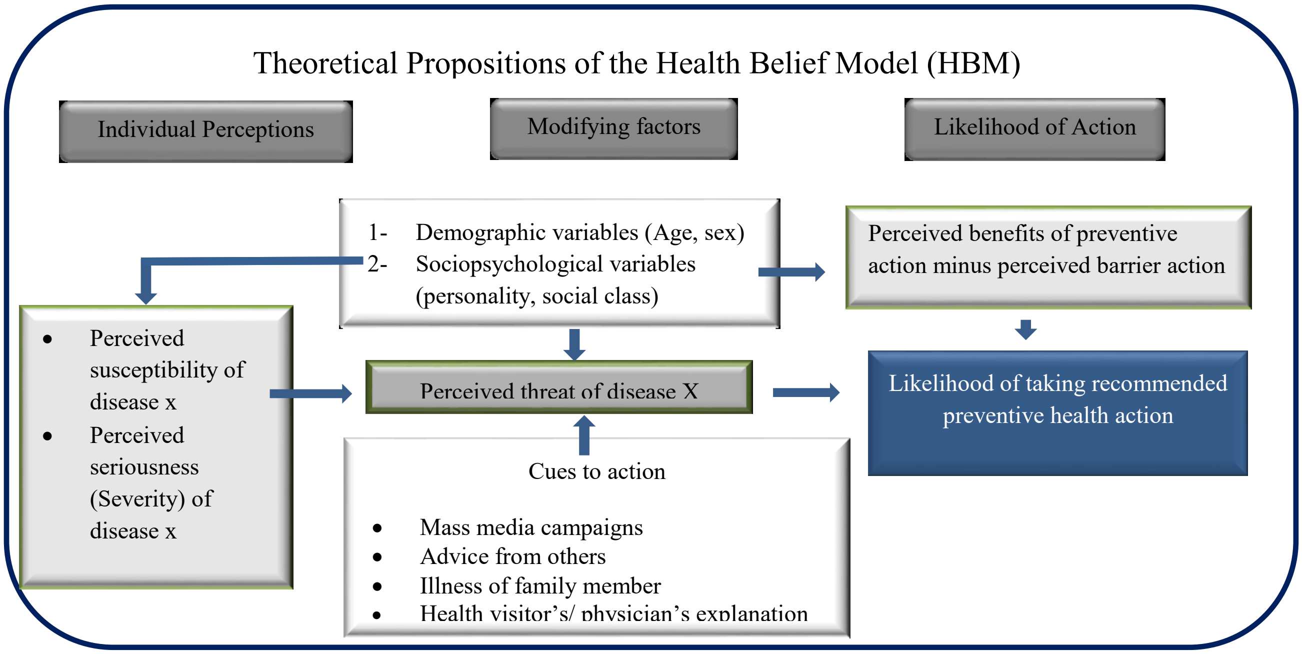


Figure A.4

The Health Belief Model. Retrieved from The health belief Model and personal health behavior (1974) by M. Becker, *Health Education Monograph,* 2, 324-47



Appendix B: Summery of Literature Reviews on Belief System

Author-Year	Methodology	Purposes	Applied Term	Themes/Quotes	Outcomes
Cottrell, Denaro, & Emmerton, 2013	Mixed Method	To identify core beliefs about the medicine's impact on adherence	Beliefs	Beliefs of adherent patients about the medications: • "related to water," • "affect the heart," • "related to weight," • "benefit to the heart"	Patients who were adherent were more likely to hold the perception that their medicines and self-care activities were related to water and weight and to affect and benefit the heart
Macinnes, J. (2013)	Quantitative	To determine relationships between treatment beliefs and the performance of self-care in community HF patients.	Beliefs	N/A	Treatment beliefs significantly predict self-care behavior
Zhang, 2012	Quantitative	Whether considering the compatibility of self-care to valued life goals can improve the prediction of self-care adherence	Motivations -Values-	N/A	Motivations are predictors of adherence
Clark et al., 2009	Qualitative	To examine patients' and their informal caregivers' willingness to	Beliefs-Values	• Faith and views about health professionals and services as	Beliefs about the local health system, and work related values link to seeking help

		undertake effective HF self-care		determinants of self-care • Values linked to culture, history, and place	
van der Wal et al., 2006	Quantitative	To examine all dimensions of adherence and its related factors in one HF population.	Beliefs	N/A	Compliance was related to patients' beliefs (OR ¼ 1.78; CI 1.18–2.69)
van der Wal et al., 2007	Quantitative	To examine the association of beliefs (about medication, diet, and symptom recognition), compliance (medication, diet, and daily weighing),	Belief-Attitudes		Beliefs as barriers: • Diuresis during the night (57%), • The taste of food (51%) • Limited ability to go out (33%). • Forgetting to weigh daily (26%). The direct relationship between depression in addition to poor knowledge and+ experiencing more barriers to compliance.
Keawe'aimoku Kaholokula, Saito, Mau, Latimer, & Seto (2007)	Qualitative	To identify the health beliefs, attitudes, practices, and social and family relations important in HF treatment	Beliefs-Attitudes	• Heart failure social support Patient • Informational supports • Family's knowledge of illness and medications • Training of caregivers • Tangible-instrumental support • Family offering and sharing in care	Adherence of Pacific Islanders to HF interventions is affected by an array of psychosocial and socio-cultural factors.

				giving responsibility • Respite for caregivers in the family • Barriers to HF management Patient • Lack of knowledge of HF • Poor doctor–patient communication • Lack of trust for physicians • Financial burdens • Making needed diet changes • Competing demands on time	
Smedt et al., 2012	Quantitative	To examine the role of beliefs about medication in coping strategies with adverse drug events	Beliefs		Patients' medication beliefs were directly related to their coping behaviors
Heo, Lennie, Moser, & Okoli, 2009	Qualitative	To identify patients' perception about how the foods they eat impact HF symptoms, their understanding of dietary recommendations received, and factors affecting their	Values-beliefs-perceptions	Food as a source of pleasure and enjoyment	The strategies suggested that patients' values and priorities regarding food are fundamental to promoting adherence. Clinicians should engage patients in a frank conversation regarding the value placed on the pleasure of eating and their perceptions of how sodium restriction alters their eating experience.

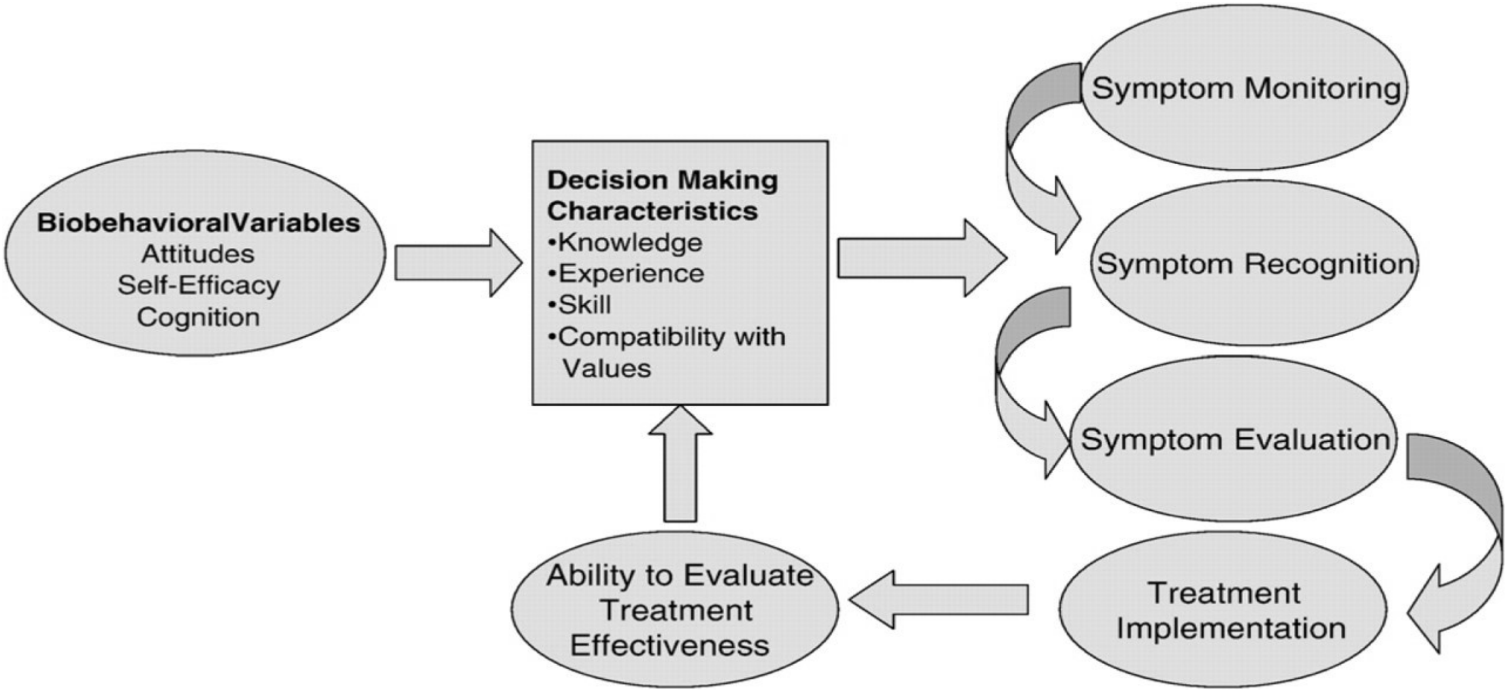
		adherence to dietary recommendations that include recommendations to follow a low sodium diet and a low-fat diet.			
Falk, Wahn , & Lidell, 2007	Qualitative	To describe how persons, living with CHF, perceived the maintenance of their daily life.	Values	Keeping up with values of life: to retain spare time activities to retain lifestyle albeit with a few adjustments	
Whitty t al., 2012	Quantitative	To examine the preferences for a program	Preference-Values		Providing care based on patient values is crucial in building a partnership between patients and health care providers and to optimize the delivery of health care services
Hicks & Holm, 2003	Quantitative	To understand patients' decision processes and the factors that influence them	Beliefs-Values		Personal beliefs and values were the second greatest influence of these participants ($p< 0.05$)
Davidson et al., 2007	Quantitative	To identify the cultural experiences of individuals with HF	Values-Beliefs-Attitudes	Religious and traditional beliefs became more important as people aged and considered their mortality	Culture provides an important context to aid interpretations of attitudes, values, beliefs and behaviors, not only in illness but in health.
Molloy et al., 2009	Quantitative	Whether beliefs about HF were associated with adherence to ACEI.	Beliefs		HF patients who believed that their illness had a more chronic (longer term) time frame and had beliefs about the greater consequences of HF on their lives were less likely to adhere to ACEI.

Horowitza, Stephanie, & Reinb, 2004		How patients' perceptions and understanding of CHF affected their behavior.	Beliefs-perceptions-Attitudes	Inability to prevent exacerbation –as a belief that impacts adherence	
Welsh et al., 2013	Quantitative	To examine the effects of an intervention on attitudes, subjective norm, and perceived behavioral control towards following a low-sodium diet.	Attitudes-beliefs		Attitudes subscale scores were higher in the intervention group at 6 weeks ($p<0.01$).
Strömberg, 1999	Qualitative	To identify factors influencing compliance with prescribed treatment in patients with chronic HF.	Attitudes-Beliefs		Compliance was influenced by the personality of the patient, the disease, the treatment, social activities, social relationships, and health care professionals.
Horne & Weinman, 1998	Quantitative	To examine the relationship between beliefs and adherence	Beliefs-Attitudes		Medication beliefs were more powerful predictors of reported adherence
Reigel et al., 2006	Mixed	self-care after receiving a motivational intervention	Values-Beliefs	Theme: making it fit (acknowledging cultural beliefs, overcoming barriers and constraints, negotiating an action plan)	The specific approaches were individualized based upon the participant's knowledge, experience, skill, and values, making it fit
Scotto, 2005	Qualitative	To identify the lived experience of patients with HF as	Values-Beliefs-		Personal values and beliefs of individuals affect adherence behaviors.

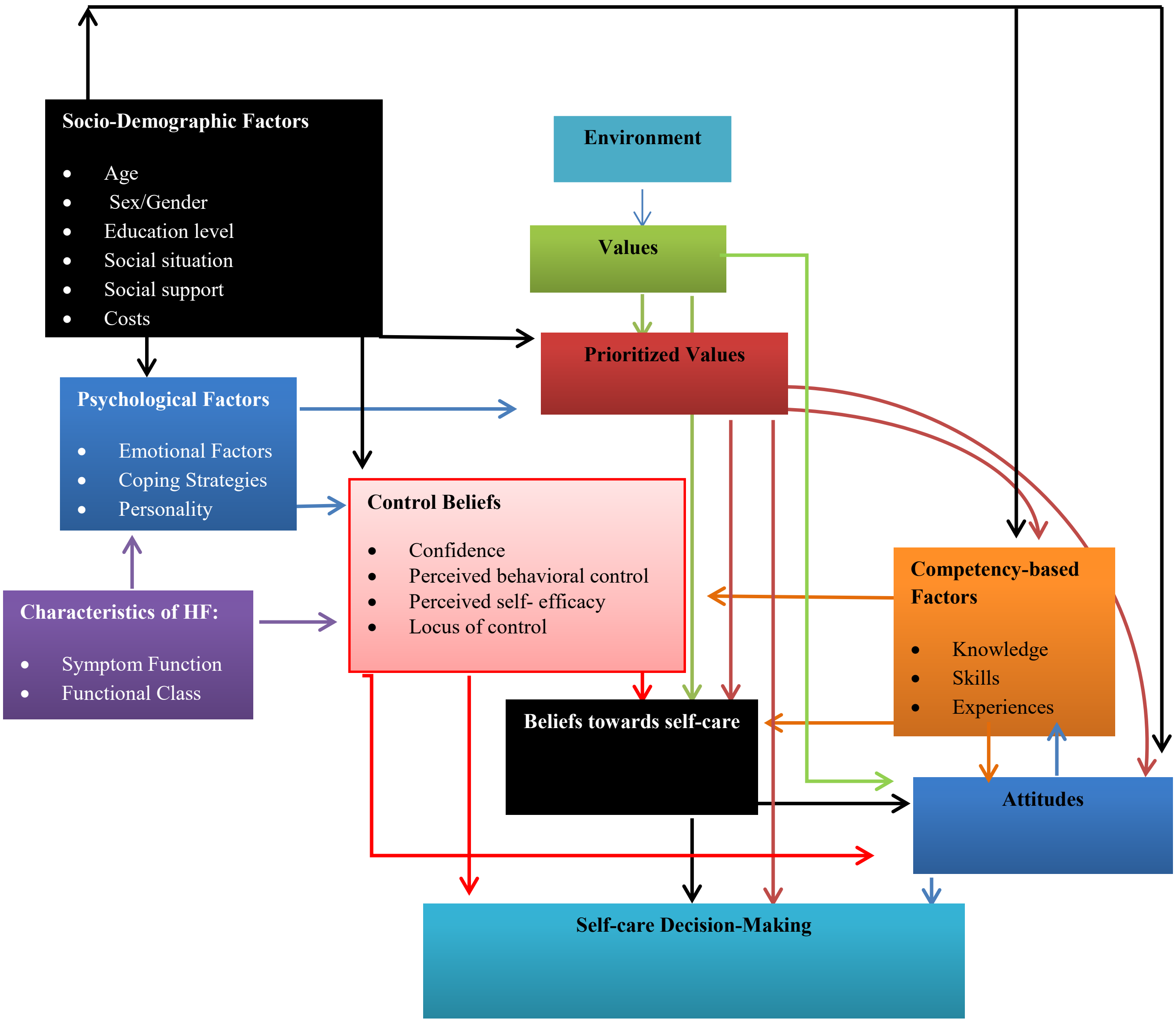
		they attempt to adhere to a prescribed regimen of care.			
Seto et al., 2010	Mixed	To assess the attitudes of HF patients and their health care providers from a heart function clinic in a large urban teaching hospital toward the use of mobile phone-based remote monitoring.	Attitudes		Patients and clinicians were willing to use the system but several barriers to implementation of such a system have been cited.
De Smedt, Denig, van der Meer, Haaijer-Ruskamp, & Jaarsma, 2011	Quantitative	To identify the relationship between HF patients' illness perception and medication beliefs and self-reported ADEs (symptomatic adverse drug events).	Beliefs		General beliefs about medication overuse (OR 1.07; 95% CI 1.01-1.13) were independently associated with experiencing ADEs. HF patients who perceive a high number of disease symptoms and have negative medication beliefs are at higher risk of experiencing self-reported ADEs.
Percival, Cottrell, & Jayasinghe, 2012	Quantitative	To identify HF patients' beliefs towards their medications and how these beliefs relate to adherence	Beliefs		Patients with a strong necessity score of Beliefs about Medicines Questionnaire (BMQ) had significantly higher self-reported adherence compared to patients with a strong concerns score (21.5 vs. 18.0, $p = 0.006$).

Appendix C: Decision-making Model of Heart Failure Self-care Management

Decision-making Model of Heart Failure Self-care Management. Retrieved from a typology of heart failure self-care management in non-elders (2008) by V. V. Dickson, J. A. Deatrick and B. Riegel, *European Journal of Cardiovascular Nursing*, *7*, p. 171-1



Appendix D: The Interrelationships between Influential Factors and Self-Care Decision-



Appendix E: Concept Analysis: Detailed Methodology

Due to word length limitations, it was not possible to include a detailed and comprehensive overview of the method employed in the manuscript of the concept analysis study developed for publication and included in Chapter 2, above. Accordingly, this appendix provides such an overview for the study, whose purpose, as noted above, was the current use of the concept of patients' values, and identify a definition.

Data sources. Given that the literature across the nursing, medicine, psychology, sociology, and theology disciplines contributes to our understanding of the concept of patients' *values*, and because ignoring a specific database may threaten the validity of the study (Morse, 2000), a search was conducted via CINAHL, MEDLINE, PsycINFO, ATLA Religion Database, Social Sciences Citation Index, Philosophers Index with Full Text, Religion and Philosophy Collection, Books: Library Ebsco Discovery Service. Examining studies from different disciplines, and working with a librarian to determine a comprehensive search strategy, allowed triangulation, helped to ensure robust analysis, and avoided missing important work, which may occur when computerized databases and indexing tools alone are used. Hand searching was also necessary because not all issues in some journals were accessible through the University of Alberta library website. In order to control the number of citations, and ensure the concept of '*patients' values'* is stated in the literature, we used the terms '*patient value**' OR '*patient preference**' (because these terms are often used interchangeably).

Selecting literature. The search yielded 914 citations retrieved via Medline (n=423), PsycINFO (1806 to Present) (n=108), CINAHL (n=139), Social Sciences Citation Index (n=112), Religion and Philosophy Collection (n=12), Philosophers Index with Full Text (n=36), ATLA Religion Database with ATLASerials (n=41), Books: Library Ebsco Discovery Service (n=43). All bibliographic records were catalogued into RefWorks version 2.0– a university Alberta' web-based citation management program, which is the service arm of the Ontario Council of University Libraries and hosts the Canadian RefWorks accounts (Ontario Council of University Libraries, n.d.). I exported all references from Refworks to an excel spreadsheet. All references that met the inclusion criteria were included in this study. Then the full texts of articles were read. Of 914 citations retrieved via databases, 880 were excluded for unavailability (n=6), duplication (n=266), lack of relevance (n=632), full texts written in non-English (n=10), could not explicate aspects of the key elements of the concept (n=201). Thereafter, an additional 88 books and articles were yielded via forward backward citations tracking methods. I prioritized and included "key references" which are "theoretically rich" (Morse, 2000). Three books (Rokeach, 1964, 1973, 2000) and two articles (Schwartz, 2007, 2012) were selected as highly-cited references which have a high influence on the concept also were considered as "landmark" (Rodgers, 2000) and were thus prioritized in this inclusion. This was identified from the number of citations that were found and reported during the literature search. To ensure rigorous sampling, an audit trail was maintained documenting inclusion / exclusion decisions and the accompanying rationale.

This strategy yielded a total of 121 books and articles that could explicate aspects of the key elements of the concept of patients' values. References were grouped according to the theoretical perspective that each paper was grounded in: medicine (46), nursing (28), psychology/sociology (34), ethics (5), philosophy (5), and theology (3).

Data collection. The thematic analysis involved a systematic approach to data collection and analysis. As such, in order to collect data systematically, to show the process of coding, and to indicate how the codes are associated with each other (Guest, MacQueen, & Namy, 2012), a codebook developed (Appendix F). The first part of the codebook included a set of theory-driven codes which were developed from the elements of evolutionary concept analysis; they included attributes, antecedents, related concepts, surrogate terms, and references. The structure of these initial codes consisted of six components, including the code name/label, brief definition, full definition, when to use, and when not to use (Guest, MacQueen, & Namy, 2012). These initial codes also determined the questions that guided me in extracting all data for concept analysis, as follows.

Attributes**,** which are the key characteristics of a concept (Rodgers, 2000), were investigated by attempting to answer the following questions: What are the characteristics of the concept of *values*? How are values presented? How are values described and understood? *Antecedents* were defined as events, phenomena that occur prior to the concept (Rodgers, 2000). Hence, in this study, the antecedents were identified through the questions of what events or phenomena preceded the application of values in various situations. What are the contextual or individual factors that contribute to the concept of *values*?

Surrogate terms, which are alternative terms with similar meanings (Rodgers, 2000), were also investigated through the use of guiding questions: Are other terms applied for the same or a similar purpose as the concept of *values*? What are the multiple ways of expressing the concept of *values*? *Related concepts* are terms that have some association with the concept, but have different attributes (Rodgers, 2000). Hence, related concepts have to be distinguished from surrogate terms. To that end, the major question is whether authors use other terms in conjunction with the concept of *values* that have different characteristics. *References* were defined as the situations in which a concept occurs (Rodgers, 2000). These was examined by asking the following question: In which situations and contexts do values function? Finally, *consequences* are the results that happen after an instance of a concept occurs (Rodgers, 2000). The consequences of values were investigated through the question of the outcomes of values.

This step ensured that the data collection process is aligned to and consistent with the objectives and outcomes of the study (Guest, MacQueen, & Namy, 2012).

In order to collect data based on the initial codes, an extraction form was developed (Appendix G). Each included article was identified by a digit (indicating the number of the reference) followed by a letter representing, respectively, the disciplines of nursing (A), medicine (B), psychology (C), sociology (D), or theology (T). This identification made it easy to distinguish the data from different disciplines. References were read frequently to extract data relevant to the attributes, antecedents, references, surrogate terms, related concepts, consequences, and exemplars of concepts, which were recorded on an extraction sheet (Appendix G).

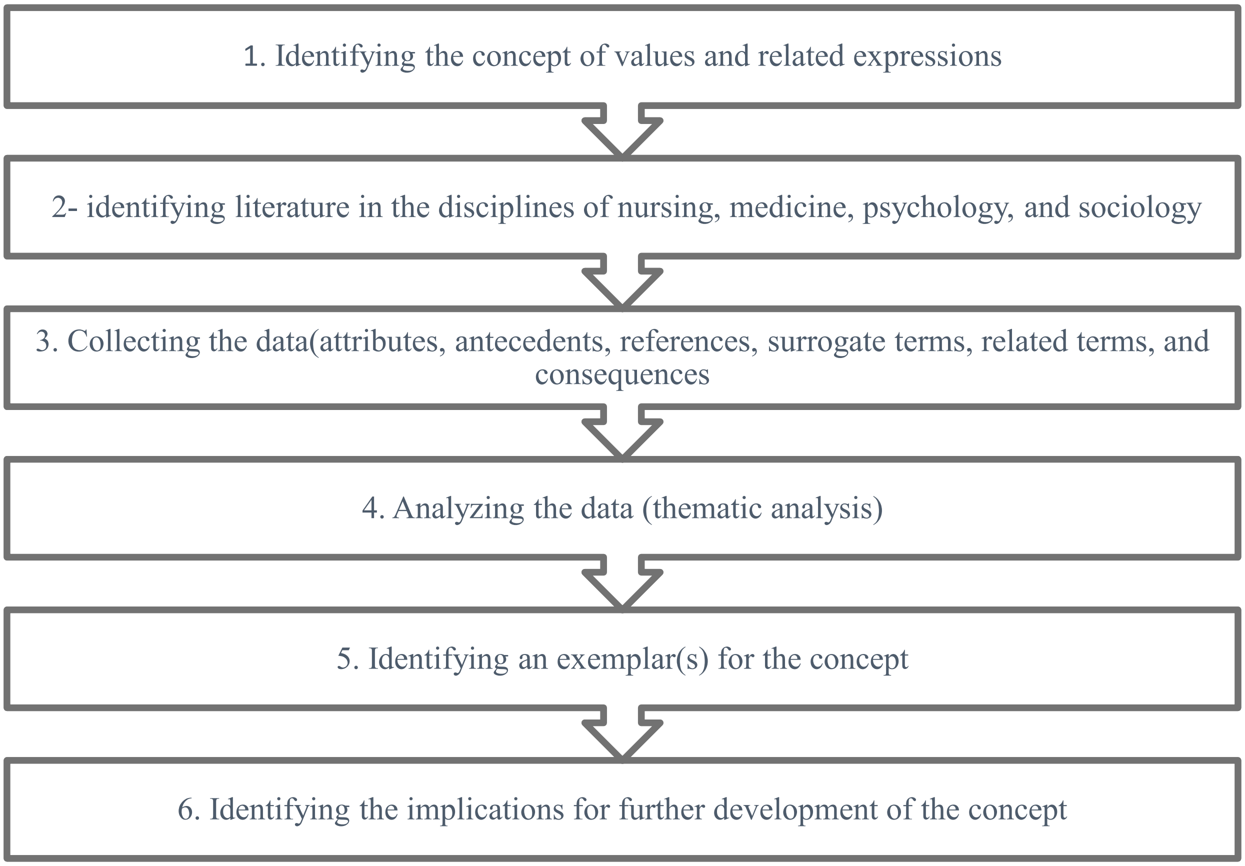
To record data on the extraction form, text segmentation was first applied as a tool (Guest, MacQueen, & Namy, 2012). That allowed me to review the texts systematically and segment the parts of the texts that are related to the initial codes defined in the codebook.

While reading and re-reading each included article, the segment of the study that reflected data regarding attributes related to the concept of values was identified. It was also tagged with a number which referred back to the number of the initial code in the codebook (Appendix F). All segments that were identified regarding *attributes, antecedents, related concepts, surrogate terms,* and *references* were cited in the extraction form for each literature piece with page and paragraph numbers. This step facilitated the investigation of the similarities, differences, and relationships across thematic components, and allowed me to return to the full text easily (Guest, MacQueen, & Namy, 2012).

Analysis. Analyses were carried out separately in five stages (Table E.1) focusing on literature in the following orders: 1) nursing, 2) medicine, 3) psychology, 4) sociology and, 5) theology. Data related to each element of the concept were then compared on the basis of their use in each discipline. This method provided more comprehensive clarity (Rodgers, 2000) for the concept analysis. It also allowed me to identify the extent of agreement and disagreement among disciplines by comparing the data (Rodgers, 2000).

Table E.1

Steps of Rodgers' Evolutionary Concept Analysis of Values



1. Identifying the concept of values and related expressions

2- identifying literature in the disciplines of nursing, medicine, psychology, and sociology

3. Collecting the data(attributes, antecedents, references, surrogate terms, related terms, and consequences

4. Analyzing the data (thematic analysis)

5. Identifying an exemplar(s) for the concept

6. Identifying the implications for further development of the concept

To achieve all of this, a thematic analysis was carried out. This method allowed me to move beyond words and phrases to identify implicit and explicit ideas (Guest, MacQueen, & Namy, 2012).

The stage of segmenting described in the data collection section (above) was followed by the stages of discovering themes, winnowing themes, turning themes into codes, and creating an effective codebook. Hence, this also included the next group of codes from the raw data – data-driven codes (Miles and Huberman 1994) for each theory-driven category. In this study, a *theme* was understood as “a phrase or sentence that identifies what a unit of data was about and/or what it means” (Saldana, 2009, p.139). In the first step, we identified themes by first refreshing our understanding of the analytic objectives, and then rereading the data by focusing on identifying, for example, how the author describes *values* (Rodgers, 2000). Drawing on a pre-review of the literature, a theme for *values* may, for instance, be “values differ between people.” Second, winnowing themes involved trying to identify implicit themes through deep analytic probing. According to Guest and colleagues (2012), because the chances are that these silent themes were less grounded as a result of our interpretation, an iterative approach was applied in this step. First, the text was read and themes proposed. Second, the themes were refined into codes along with comprehensible definitions. In order to maintain a systematic and replicable approach, all suggested codes with “suggested code definition” elements were provided in a table in the codebook.

These steps were conducted independently for each discipline through frequently organizing and reorganizing comparable patterns in the literature “until a cohesive, comprehensive, and relevant system of descriptors was generated” (Rodgers, 2000, p. 95). However, this process of reduction was not applicable to the surrogate terms and related concepts, given that they comprised just one or two words. As the purpose of the concept analysis was to identify both consensus and failure to define a concept, this study considered not only the similar points in the literature, but also the outliers.

Identifying an exemplar. For further clarification, this study attempted to identify an exemplar – that is, an “ideal”, “practical” and “universal enough” example which represents the characteristics of the concept of *values* in relevant contexts rather than constructing an ideal exemple (Rodgers, 2000).

Interpretation. Although in Rodgers’ concept analysis method the interpretation of the results does not include claiming a definitive answer or a definition for the under-studied concept, this study tried to focus both on providing a foundation to clarify the concept (Rodgers, 2000) – as the ultimate purpose of this method– and define the concept of *values* for the purpose of using it in other studies in this project.

Rigour. Several of the strategies discussd above seek to achieve rigour. Confirmability was established by checking and rechecking the data throughout the study. We also discussed all of the stages of this study (e.g. data collection strategies and the analysis process), and reviewed all ambiguities to reach consensus in each case. This process was also contributed to the investigator triangulation due to examining the findings by two professors and a PhD student, Moreover, methodological triangulation in this study was addressed by including theoretical literature and qualitative, quantitative studies yielded from different disciplines. It, however, required more literature. Likewise, it required more time to analyze the data.

Furthermore, given that it is important to take into account the necessity of developing a comprehensive audit trail from the beginning of the study (Rodgers & Cowles, 1993), this study included the following documentation in the audit trail. 1) *A structured data collection tool*: This tool guides data collection and keeps records of the summaries, pitfalls, and failures regarding each study (Appendix G). In addition to general and specific data about values, a summary of each selected literature was provided in the extraction form immediately after in-depth reading of each selected literature. 2) *Reflexive journal*: In this document, reflexivity or the process of self-examination has been taken into account from the first phase of this study by constantly reflecting my assumptions and my personal beliefs (Russell & Kelly, 2002; Ahern, 1999). These notes continued to be recorded in electronic documents on a daily basis. This raised the awareness of personal bias to a conscious level (Rodgers & Cowles, 1993). Also, the rationale for all decisions also were addressed in order to maintain "neutrality" (Lincoln & Guba, 1985). 3) *Literature search– documentation:* The literature search with details including applied key words, all restrictions, and results, were recorded in the audit trail. Analytic decisions regarding the selection of the literature was addressed from different aspects, such as the extent and the nature of the contribution of each discipline to understanding of the concept of *values*, in addition to any uncertainty about this concept in the above mentioned disciplines. 4) *Analytic notes:* All phases of the analysis of qualitative data were immediately and comprehensively documented in detail in order to ensure a rigorous analysis.

Appendix F: Codebook
Initial codes

This table is the first section of the codebook which lists initial theory-driven codes. The first column is the name of the code. The second column is the assigned number for the code. This number is used for segmenting in the articles. The third column is the code name that is applied during study. The last column is the definition of the code in terms of Brief definition, full definition, when to use, and when not to use.

Structural Coding. Adapted from Applied thematic analysis (2012) by G. Guest, K. M. MacQueen, and E. E. Namey. Thousand Oaks: SAGE Publications.

Code	#	Code Name	Structural Code Definition
Attributes	**1**	**Att**	**Brief Definition:** The main part of definition **Full Definition:** This is usually the characteristics of the values. Extraction guide: What are the characteristics of the concept of *values*? How are values presented? What do values refer to? **When to Use:** Use this code to capture how authors define values which usually start at the beginning of the definition and illuminate what values are and may include a word or words. **When Not to Use:** Do not use this code for other part of the definition that is covered by other codes.
Antecedents	**2**	**Antec**	**Brief Definition:** preliminary events **Full Definition:** Antecedents are events, phenomena that occur prior to the concept. They are sought via following questions: What are events or phenomena precede the concept of *values*? What are the contextual or individual factors that contribute to the concept of *values*? **When to Use:** Use this code to capture events or phenomena that precede the concept of *values*. This can be contextual or individual factors that contribute to the concept of *values*. **When Not to Use:** Do not use this code for finding for references which are situations and contexts that values function.
Surrogate terms	**3**	**Sur**	**Brief Definition:** Substitute concepts **Full Definition:** Surrogate terms are alternative terms with similar meanings. Extraction guide: What are other terms that applied for the same or similar purpose? What are the multiple ways of expressing the concept of *values*? **When to Use:**

			When Not to Use: Do not use this code for the related concepts which are different terms for different purposes but only not clearly differentiate from values**.**
Related concepts	**4**	**Rel-Con**	**Brief Definition:** Close concepts **Full Definition:** Related concepts are terms that have some association with the concept, but have different attributes. Extraction guide: Do author(s) use other terms in conjunction with the concept of *values* but have different characteristics? **When to Use:** Use this code to capture the other terms which are close to values in terms of the conceptualization but are considered different **When Not to Use:** Do not use this code for surrogate terms which are different terms but for the same purposes as values
References	**5**	**Ref**	**Brief Definition:** Context **Full Definition:** References are defined as the situations in which a concept occurs. Extraction guide: In which situation and context do values function? **When to Use**: Use this code for the situation that values are discussed. **When Not to Use:** Do not use this code for antecedents which are events or phenomena that precede values.
Consequences	**6**	**Cons**	**Brief Definition:** Results **Full Definition:** consequences are the results that happen after an instance of a concept occurs Extraction guide: What is the outcome of values? **When to Use:** Use this code to capture the ultimate results of the function of values. **When Not to Use:** Do not use this code for the results of the related concepts.

Appendix G: Extraction Sheet I

Identification Number: ———— Discipline (Letter) :———— Date: ————

Title:			
Author/S (Year):			
Setting Country:			
Type of Source:	Qualitative Study ☐ Quantitative Study ☐ Mixed Method study ☐ Systematic Review☐ Non-Research Document☐		
Publication type	Full text articles ☐ Abstract ☐ Book Chapter ☐ Others ☐ …………………..		
The Discipline of The Primary Author:	A-Nursing ☐ B- Medicine ☐ C-Psychology ☐ D-Sociology ☐		
Journal			
Number of citations			
Population of study	Patients ☐ Family care givers☐ Health care professionals ☐ Others (Specify) …		
Data about the concept of Values			
Initial Codes	*Results*	*Page*	*Para*
1-Attributes related to concept of values	*What are the characteristics of the concept of values? How are values presented? What do values refer to?*		
2- Antecedents	*What do events or phenomena precede the concept of values?* *What are the contextual or individual factors that contribute to the concept of values?*		

3- Surrogate terms	*What are other terms that are applied for the same or similar purpose?* *What are the multiple ways of expressing the concept of values?*		
4- Related concepts	*Do author(s) use other terms in conjunction with the concept of values but have different characteristics?*		
5-References	*In which situation and context values' function is appeared?*		
6- Consequences	*What is the outcome of values?*		
Exemplar (s)	*Is there a practical example to present the characteristics of the concept of values?*		

Rationale for including this document		
Challenges, pitfalls		
Summary /notes	Immediately After reading Date:	
	After re-reading Date:	
	After re-reading Date:	
Debriefing		

Appendix H: Surrogate Terms and Related Concepts

Table H.1

Related Concepts

Expression of a Framework and a Phenomenon

Values-based Practice (Reich, 1982; Lawlor & Braunack-Mayer, 2004; Petrova, Dale, & Fulford, 2006).
Shared decision making (Petrova et al., 2006; Sinding, 2006; Kissane, Bultz, Butow, & Finlay, 2010).
Patient client-centered approach/care or Person client-centered approach/care (Vanderford et al., 1992; McCracken & Yang, 2006; Hirsch & Abernethy, 2012).
Values Assimilation (Kelly, 1990).
Values Clarification (DiCenso, Guyatt, & Ciliska. 2014; Kissane et al., 2010; Masters, 2009; Gaudiano et al., 2013; Llewellyn-Thomas & Crump, 2013).
Implicit Values Elicitation (DiCenso, et al. 2014).
Explicit Values Elicitation (DiCenso, et al. 2014).

Valuation

Expected utility/ Expected Values/ Valuation (Lichtenberg, 1983; Lee et al., 2009; Young et al., 1996; Kalish & Collier, 1981; Ubel & Loewenstein, 1997; MacLean et al., 2012).	The weighted values (provide a numeric value) for the therapeutic alternatives, health states, or health outcomes, which are based on patients' priorities.

Alternative Concepts

Attitudes (Farrell, 1987; Patterson & Blocher, 1989; Kelly, 1990; Lawler, 1998; Lawlor & Braunack-Mayer, 2004; Segalla, 2006; Masters, 2009)
Beliefs (Kelly, 1990; Vanderford et al., 1992; Bosek & Savage, 2007; Cody, 2013; Charles & Gafni, 2014).
Characteristics/ character traits/ personality traits (Sinding, 2006; Kinnane & Suziedelis, 1966; Beckstran, 1978; Reich, 1982; Kelly, 1990; Austgard, 2007; Altamirano-Bustamante et al., 2013; Rid & Wendler, 2014)
Choices (Kinnane & Suziedelis, 1966; Sinding, 2006; Pollak et al., 2011)
Convictions (Ridley, 1998)
Demeanor (Bosek & Savage, 2007)
Designated surrogate input (Wilkinson & Truog, 2013)
Goals (Jensen & Mooney, 1990; Kelly, 1991; Nicoll et al., 2004; Bosek & Savage, 2007; Quill, 1993)
Interests (Kinnane & Suziedelis, 1966; Kelly, 1990; Patterson & Blocher 1989)
Morals (Patterson & Blocher, 1989)
Moral attitudes (Kelly, 1990; Bosek & Savage, 2007)

Moral practice (Austgard, 2007)
Moral principles (Bosek & Savage, 2007)
Motivation (McCormack, 2003; Masters, 2009; Pollak et al., 2011)
Needs (Beckstrand, 1978; Kelly, 1990; Jensen & Mooney, 1990; McCormack, 2003; Austgard, 2007; Meadowcroft, 2008)
Norms (Austgard, 2007; Kelly, 1990; Segalla, 2006; Kuschel & Mieth, 2001)
Preferences (Jensen & Mooney, 1990; Quill, 1993; Bosek & Savage, 2007)
Traits (Kinnane & Suziedelis, 1966; Kelly, 1990; Altamirano-Bustamante et al., 2013)
Virtue (Altamirano-Bustamante et al., 2013)
Wants (Jensen & Mooney, 1990)
Wishes (Thomasma, 1989; Kikuchi & Simmons, 1999; Chiong, 2013, McCormack, 2003)

Appendix I: Extraction Sheet II

Extraction Sheet II: Heart Failure Patients' Values and Self-care Decision-Making

First Author (Year): ---

Journal: ---

Focus: --

Reviewer (*Check*): **MK** ☐ **AC** ☐

Population: ---

Group (*Check all applicable*)

☐ Patients ☐ Health Professionals

☐ Family / Caregivers

☐ Other (specify): --

Sample

☐ Men only ☐ Women only ☐ Mixed

Type

☐ Convenience ☐ Purposive ☐ Theoretical

☐ Other: ____________________

Size:

	Number	%
Males		
Females		
Total		

Other: ____

If patients:

Mean Age: _______________Range: ___________to _____________years

Males

Mean Age: __________________Range: _____________ to ___________________years

Females

Mean Age: __________________Range: _________________ to __________________years

If professionals:

Type (s):________________

Setting Country(s) ______USA_______________________

METHOD (NB: not necessarily label of author)

Approach (Principle only)

☐ Grounded theory
☐ Interpretive descriptive
☐ Mixed methods
☐ Other: _______________________________________
☐ Ethnography
☐ Critical theory
☐ Phenomenology

Data collection methods

1. ☐ Face-to-face ☐ Telephone

2. ☐ Interview: un-structured
☐ Interview: semi-structured
☐ Interview: structured

☐ Focus group

☐ Other (specify): ————————————

1. **Main strengths:**

2. **Main concerns:**

Overall quality rating:

High ☐ **Medium** ☐ **Low** ☐

Findings:

Appendix J: Mixed Methods Appraisal Tool (MMAT)

Mixed Methods Appraisal Tool (MMAT). Reprinted from a mixed methods appraisal tool for systematic mixed studies Reviews, by P. Pluye and colleagues, (2011). http://mixedmethodsappraisaltoolpublic.pbworks.com

Types of mixed methods study components or primary studies	**Methodological quality criteria (see tutorial for definitions and examples)**	**Responses**		
		No	Can’t tell	Comments
Screening questions (for all types)	- Are there clear qualitative and quantitative research questions (or objectives*), or a			
	- Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).			
	Further appraisal may be not feasible or appropriate when the answer is ‘No’ or ‘Can’t			
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question			
	1.2. Is the process for analyzing qualitative data relevant to address the research question			
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the			
	1.4. Is appropriate consideration given to how findings relate to researchers’ influence, e.g., through their interactions with participants?			
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence			
	2.2. Is there a clear description of the allocation concealment (or blinding when			
	2.3. Are there complete outcome data (80% or above)?			
	2.4. Is there low withdrawal/drop-out (below 20%)?			
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?			
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups			
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants parable, or do researchers take into account (control for) the difference between these groups?			

	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?			
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question			
	4.2. Is the sample representative of the population understudy?			
	4.3. Are measurements appropriate (clear origin, or validity known, or standard			
	4.4. Is there an acceptable response rate (60% or above)?			
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the			
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address			
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative			
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative			

ixed methods study components or primary studies	**Methodological quality criteria**
1. Qualitative Common types of qualitative research methodology include: A. Ethnography The aim of the study is to describe and interpret the shared cultural Behavior of a group of individuals. B. Phenomenology The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals. C. Narrative The study analyzes life experiences of an individual or a group.	**1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?** E.g., consider whether (a) the selection of the participants is clear and appropriate to collect relevant and rich data; and (b) reasons why certain potential participants chose not to participate are explained.
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)? E.g., consider whether (a) the method of data collection is clear (in depth interviews and/or group interviews, and/or observations and/or documentary sources); (b) the form of the data is clear (tape recording, video material, and/or field notes for instance); (c) changes are explained when methods are altered during the study; and (d) the qualitative data analysis addresses the question.
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? E.g., consider whether the study context and how findings relate to the context or characteristics of the context are explained (how findings are influenced by or influence the context). "For example, a researcher wishing to observe care in an acute hospital around the clock may not be able to study more than one hospital. (…) Here, it is essential to take care to describe the context and particulars of the case [the hospital] and to flag up for the reader the similarities and differences between the case and other settings of the same type" (Mays & Pope, 1995). The notion of context may be conceived in different ways depending on the approach (methodology) tradition.

D. Grounded theory Generation of theory from data in the process of conducting research (data collection occurs first). E. Case study In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country. F. Qualitative description There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic	**1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?** E.g., consider whether (a) researchers critically explain how findings relate to their perspective, role, and interactions with participants (how the research process is influenced by or influences the researcher); (b) researcher's role is influential at all stages (formulation of a research question, data collection, data analysis and interpretation of findings); and (c) researchers explain their reaction to critical events that occurred during the study. The notion of reflexivity may be conceived in different ways depending on the approach (methodology) tradition. E.g., "at a minimum, researchers employing a generic approach [qualitative description] must explicitly identify their disciplinary affiliation, what brought them to the question, and the assumptions they make about the topic of interest" (Caelli, Ray & Mill, 2003, p. 5).

Types of mixed methods study components or primary studies	**Methodological quality criteria**
2. Quantitative randomized controlled (trials) Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers). Key references: Higgins & Green, 2008; Porta, 2008; Oxford Center for Evidence based medicine, 2009.	**2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?** In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance, and researchers describe how the randomization schedule is generated. "A simple statement such as 'we randomly allocated' or 'using a randomized design' is insufficient". *Simple randomization:* Allocation of participants to groups by chance by following a predetermined plan/sequence. "Usually it is achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer". *Sequence generation:* "The rule for allocating interventions to participants must be specified, based on some chance (random) process". Researchers provide sufficient detail to allow a readers' appraisal of whether it produces comparable groups. E.g., blocked randomization (to ensure particular allocation ratios to the intervention groups), or stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics).
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? *The allocation concealment protects assignment sequence until allocation.* E.g., researchers and participants are unaware of the assignment sequence up to the point of allocation. E.g., group assignment is concealed in opaque envelops until allocation. *The blinding protects assignment sequence after allocation.* E.g., researchers and/or participants are unaware of the group a participant is allocated to during the course of the study.
	2.3. Are there complete outcome data (80% or above)? E.g., almost all the participants contributed to almost all measures.

	2.4. Is there low withdrawal/drop-out (below 20%)? E.g., almost all the participants completed the study.

Types of mixed methods study components or primary studies	Methodological quality criteria
3. Quantitative non-randomized Common types of design include (A) non-randomized controlled trials, and (B-C-D) observational analytic study or component where the intervention/exposure is defined/assessed, but not assigned by researchers. A. Non-randomized controlled trials The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups.	**3.1. Are participants (organizations) recruited in a way that minimizes selection bias?** At recruitment stage: For cohort studies, e.g., consider whether the exposed (or with intervention) and non-exposed (or without intervention) groups are recruited from the same population. For case-control studies, e.g., consider whether same inclusion and exclusion criteria were applied to cases and controls, and whether recruitment was done independently of the intervention or exposure status. For cross-sectional analytic studies, e.g., consider whether the sample is representative of the population.

B. Cohort study Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal). C. Case-control study Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective). D. Cross-sectional analytic study At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population sub-groups according to the presence/absence (or level) of the intervention/exposure. Key references for observational analytic studies: Higgins & Green, 2008; Wells, Shea, O'Connell, Peterson, et al., 2009.	**3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?** At data collection stage: E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) the measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure. For non-randomized controlled trials, the intervention is assigned by researchers, and so consider whether there was absence/presence of a contamination. E.g., the control group may be indirectly exposed to the intervention through family or community relationships.
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? At data analysis stage: For cohort, case-control and cross-sectional, e.g., consider whether (a) the most important factors are taken into account in the analysis; (b) a table lists key demographic information comparing both groups, and there are no obvious dissimilarities between groups that may account for any differences in outcomes, or dissimilarities are taken into account in the analysis.
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

Types of mixed methods study components or primary studies	Methodological quality criteria
4. Quantitative descriptive studies Common types of design include single-group studies: A. Incidence or prevalence study without comparison group In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed). B. Case series A collection of individuals with similar characteristics are used to describe an outcome. C. Case report An individual or a group with a unique/unusual outcome is described in details. Key references: Critical Appraisal Skills Programme, 2009; Draugalis, Coons & Plaza, 2008.	**4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?** E.g., consider whether (a) the source of sample is relevant to the population under study; (b) when appropriate, there is a standard procedure for sampling, and the sample size is justified (using power calculation for instance).
	4.2. Is the sample representative of the population understudy? E.g., consider whether (a) inclusion and exclusion criteria are explained; and (b) reasons why certain eligible individuals chose not to participate are explained.
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.
	4.4. Is there an acceptable response rate (60% or above)? The response rate is not pertinent for case series and case report. E.g., there is no expectation that a case series would include all patients in a similar situation.

Types of mixed methods study components or primary studies	Methodological quality criteria
5. Mixed methods Common types of design include: A. Sequential explanatory design The quantitative component is followed by the qualitative. The purpose is to explain quantitative results using qualitative findings. E.g., the quantitative results guide the selection of qualitative data sources and data collection, and the qualitative findings contribute to the interpretation of quantitative results. B. Sequential exploratory design The qualitative component is followed by the quantitative. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the qualitative findings inform the	**5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?** E.g., the rationale for integrating qualitative and quantitative methods to answer the research question is explained.

quantitative data collection, and the quantitative results allow a generalization of the qualitative findings. C. Triangulation design The qualitative and quantitative components are concomitant. The purpose is to examine the same phenomenon by interpreting qualitative and quantitative results (bringing data analysis together at the interpretation stage), or by integrating qualitative and quantitative datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). D. Embedded design The qualitative and quantitative components are concomitant. The purpose is to support a qualitative study with a quantitative sub-study (measures), or to better understand a specific issue of a quantitative study using a qualitative sub-study, e.g., the efficacy or the implementation of an intervention based on the views of participants. Key references: Creswell & Plano Clark, 2007; O'Cathain, 2010.	**5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?** E.g., there is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration.
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?

Appendix J: Systematic Review: Detailed Methodology

Due to word length limitations, it was not possible to include a detailed and comprehensive overview of the method employed in the manuscript of the concept analysis study developed for publication and included in Chapter 3, above. Accordingly, this appendix provides such an overview for the study, whose purposes, as noted above, were:

- What are HF patients' reported values regarding self-care in HF?
- How do personal values affect self-care decision-making in the context of HF from patients, family caregivers, and health professionals' perspectives?

Methods. This systematic review synthesized qualitative, quantitative, and mixed-methods studies. Such an approach was suitable for this study, given that the main goal was to construct a valid model, and this method extends the richness of data (Glaser, 1994). Glaser (1994) claims that it "bring[s] out the richness of quantitative data that is seen only implicitly while the focus remains on verification" (p. 198). This method strengthened the inferences of this study through the triangulation of both qualitative and quantitative sources within a mixed-methods framework (Tashakkori, 2009, p. 38), in addition to providing the breadth and depth of understanding and corroboration (Johnson, Onwuegbuzie, & Turner, 2007, p. 123).

Definition of mixed-method research. This study has adopted the definition of mixed-methods study provided by Morse (2009), that "the [mixed-methods] study consists of a qualitative or quantitative core component and a supplementary component (which consists of qualitative or quantitative….) (p. 20).

The core components. The core component of this study was qualitative, given that the qualitative studies provided the theoretical foundation for other "supplemental components" (the complementary quantitative data) (Morse & Niehaus, 2009, p. 115). This was appropriate to consider qualitative studies as the core components, given that qualitative studies have provided unique contributions to cardiovascular outcomes (Curry, Nembhard, & Bradley, 2009), in terms of understanding the complexity of self-care in HF (Clark et al., 2009; Siabani, Leeder, & Davidson, 2013; Thomas, 2011) and identifying beliefs that underlie self-care behaviors in HF patients (Clark et al., 2009; Cottrell, Denaro, & Emmerton, 2013; Kadal et al., 2009; van der Wal, 2010).

The supplemental components. Quantitative studies, by contrast, are considered supplemental components. Although quantitative results are based predominantly on structured questions that may limit me from understanding other elements that contribute to the complexity of the phenomenon, they may still enable me to address aspects of complexity (A. Clark, personal communication, October 15, 2013). Consistent quantitative data, thus, conveys the complementary information; understanding the complexity of, for example, self-care behavior as a social phenomenon (Høy, Wagner, & Hall, 2007; Gochman, 1997, Hickey, Dean, & Holstein, 1986; DeFriese, & Woomert, 1983) is extremely difficult when strictly relying on a quantitative or qualitative research paradigm alone (Yauch & Steudel, 2003).

Advantages of applying both methodologies. Using both types of studies (i.e. qualitative and quantitative) can generate more complete (Creswell &Plano Clark, 2011, 2007), “interdependent” (Strauss & Corbin, 1990, p.32; Tashakkori & Teddlie, 2010, p. 432), and interrelated (Fielding & Fielding, 1986) data. Rigor, in the first place, was enhanced by avoiding the blind spots inherent in individual methods. For example, if we were to rely only on qualitative research as an appropriate methodology to capture the complexity of self-care, the chances are that those qualitative studies would draw on the constructivist paradigm. This paradigm guides researchers to focus only on patients’ perspectives and to marginalize the involvement of contextual factors; hence, the results may not capture the whole picture of a phenomenon.

In addition, the findings of these two methodologies are "*complementary*" (Maxwell 2010; Yauch & Steudel, 2003; Sale, Lohfeld, & Brazil, 2002; Greene, Caracelli, & Graham, 1989) which enhances their interdependence and interrelationship. This was because quantitative studies identify "that-knowledge" (Sandelowski, Voils, & Barroso, 2006) (e.g., religious beliefs impact self-care behavior), while qualitative studies identify "why –knowledge" (Sandelowski et al., 2006) (why patients with knowledge still may not adhere to self-care plans?) and what we might define as "how knowledge" (e.g. how do beliefs impact self-care behavior). Together, these forms of knowledge might explain self-care decision-making. This led me to a deeper understanding of patients' values and how they, along with other individual and contextual factors, impact HF self-care decision-making.

To achieve the above goals, a *mixed-methods monostrand conversion* design was employed.

The mixed-methods monostrand conversion design. Teddlie and Tashakkori (2009) describe the basic principles of this method as follows: The simplest of the MM designs, [involves] only one strand of a research study, yet [includes] both QUAL and QUAN components. Because only one type of data was analyzed and only one type of inference (QUAL or QUAN) was made, we labeled these designs as quasi-mixed. (p. 149). It was noteworthy that there appears to be no consensus among authors in the field on the use of terminology for this particular method. For example, *integrated design* (Sandelowski et al., 2006), and *concurrent mixed analysis* (Onwuegbuzie & Leech, 2004) are used as alternate terms for this general method. Accordingly, this study included qualitative and quantitative research. The quantitative

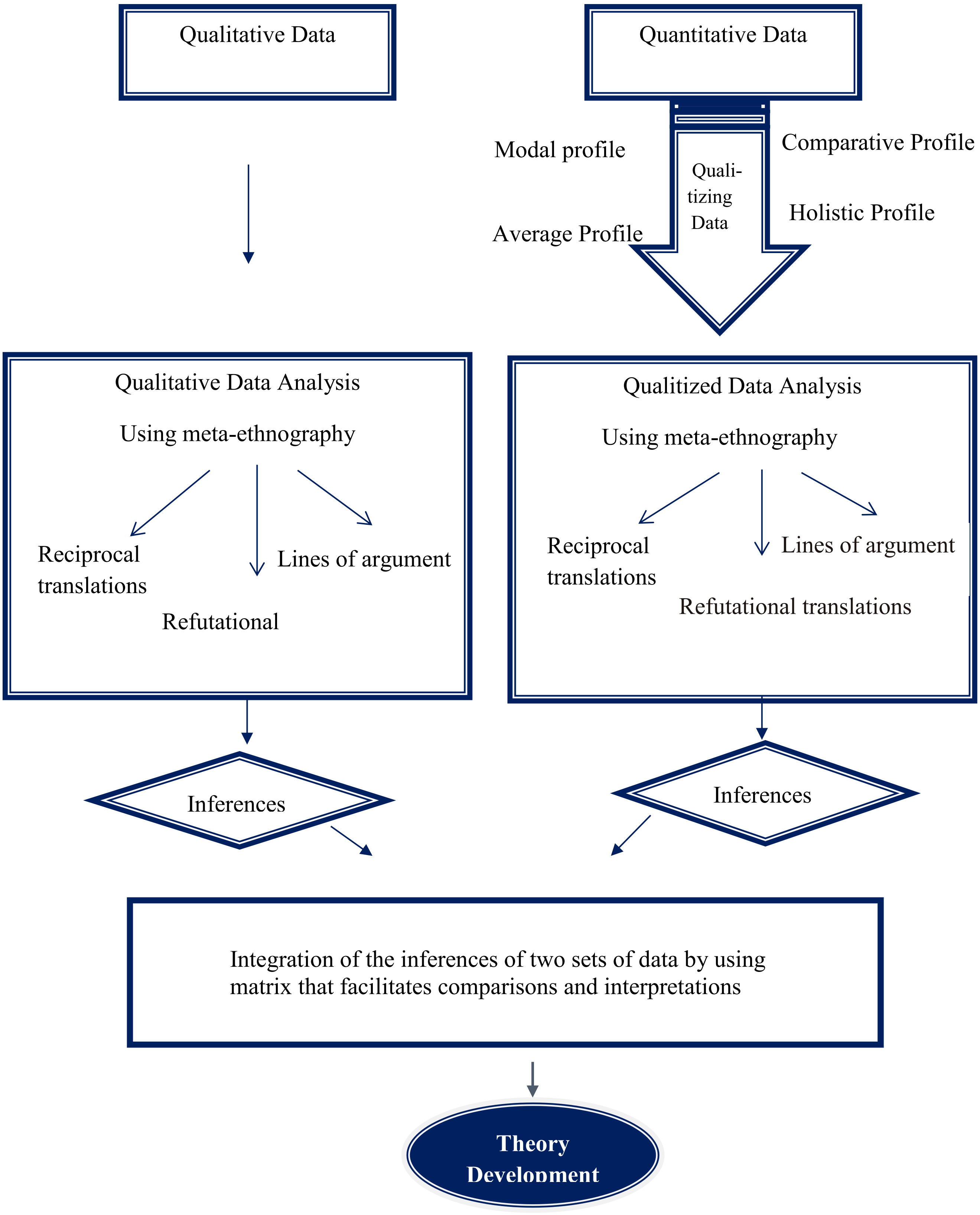


Figure J.1

Steps of Analysis in the Mixed-Methods Systematic Review data were converted into qualitative data (qualitized data) through four strategies, including modal profile, average profile, comparative profile, and holistic profile (Taskkori & Teddlie, 1998; Teddlie & Tashakkori, 2008). Thus, to answer the questions of this study, only one strand of data, which was qualitative data, were analyzed (Figure J.1). In order to analyze the qualitative data and qualitized data, meta-ethnography (Noblit & Hare, 1988), which was generally based on the constant comparison method.

Blending monostrand conversion design with a meta-ethnographic approach. To achieve this goal, as noted earlier, mixed-methods monostrand conversion design was applied to guide me in integrating the qualitative and quantitative studies. It allowed me to convert all data into a homogenous format (words). Several methods were used to analyze these data, such as latent content analysis (seeking underlying meaning) and constant comparison (Tashakkori & Teddlie 1998). However, to analyze the data, a meta-ethnographic approach as a form of systematic comparison (Noblit & Hare, 1988) was integrated into this method. This was done for several reasons:

1) Applying monostrand conversion design renders all of the data in narrative format, which enables me to employ meta-ethnography as a well-established method for synthesising qualitative research studies in health care (Campbell et al., 2011).
2) Just as the systematic search may find the literature contains similar, different, and oppositional findings, this method, being comprehensive, provides three different approaches for three kinds of findings: those that offer a line of argument, and those that occupy oppositional positions and/or are analogous and different on a particular theme. This allowed me to conduct a rigorous procedure for advancing our interpretive understanding through a comparative and interpretive process.

3) This was a systematic approach, as it provides a step-by-step description of meta-ethnography.
4) It was applicable to all qualitative studies with similar foci, given that this approach was based in translating studies into one another in order to understand how the studies are linked (Noblit & Hare, 1988). This allowed me to include a variety of studies that used different methods but that, in many cases, have attempted to interpret the results which are relevant to this study.
5) Its aim was to provide an inductive and an interpretive form of knowledge synthesis (Klein, 1989), which was in line with the purpose of this study to build a theory.
6) This enabled participation in enriching human discourse and to comprehend the reality of everyday HF self-care.
7) The importance of focusing on context in this approach was consistent with the tenets of CR, which was the theory underpinning this project.

To date there have been few studies which have attempted to synthesize qualitative and quantitative research using meta-ethnography (Dixon-Woods et al. 2005). Coincidentally, the application of this integration of mixed-methods design and meta-ethnography has been addressed in studies with more or less similar purposes as in the current study. For instance, in investigations of the impact of beliefs on behavior of people with mental health problems (Brohan et al., 2012) and on decision-making about infant feeding among migrant women (Schmied, Olley, Burns, Duff, Dennis, & Dahlen, 2013). Therefore, it was expected that the findings from this study added to the evidence around the impact values (the more central beliefs) on decision-making process by integrating mixed-methods and meta-ethnography in a

SR study. It was also anticipated that this study conjointly shed light on the strengths and weaknesses of this integration.

The meta-ethnographic process. This meta-ethnographic study was accomplished as follows, based on the work of Noblit & Hare (1988):

Phase 1: Getting started. This step, as discussed earlier, was related to the necessity of synthesizing a new interpretation of existing qualitative studies in order to achieve the goals of this study. It was necessary to determine whether this SR has already been conducted. To do so, databases such as Cochrane Library, MEDLINE, CINAHL, PsycINFO, Proquest, Embase, Database of Abstracts of Reviews of Effectiveness (DARE), Database of Promoting Health Effectiveness Reviews (DoPHER), Joanna Briggs Institute (JBI), PEDro, and The Campbell Library, were checked.

Phase 2: Deciding what was relevant to the aims of the study. The following inclusion/exclusion criteria were used to ensure that only relevant studies were included:

Inclusion criteria:

1) Studies conducted between 2000 and 2014. This range of time has been selected based on insights from:

   a) Archer's work on critical realist perspectives, which argues that the interplay between agency (such as individuals' values) and contextual factors (that underpin self-care behavior) changes over time (Archer, 2012, 1988, 2000); and

   b) Theories of basic values (Rokeach, 1973; Schwartz, 2012), which argue that basic values change gradually over time.

   As such, this time-frame allowed me to develop a theory that was applicable to our contemporary practice and research.

2) Study populations were composed of adults with HF.

3) Studies applied mixed-methods, quantitative, or qualitative methods. This method strengthened the inferences of this study and provided the breadth and depth of understanding (Johnson, Onwuegbuzie, & Turner, 2007, p. 123).
4) Studies were written in English and published in academic journals.
5) Studies contained extractable data that are explicitly or implicitly related to the patients' values and HF self-care behavior.
6) Studies contained data from patients, family caregivers, or health professionals' perspectives.

Exclusion Criteria:

1) Studies contained data from participants who have physical disabilities or mental health problems, such as a cognitive impairment or depression. These factors impacted patients' values and, thus, the validity of the data and findings of this study.

A systematic search identified potentially relevant studies and allowed me to capture a comprehensive index of all accessible citations which was linked to the quality and validity of the final product (Holly, Salmond, & Saimbert, 2012). The systematic search was conducted by a health sciences librarian on March 14, 2014 in the following databases: MEDLINE In-Process and Other Non-Indexed Citations, Ovid MEDLINE 1946-, Ovid Embase 1996-, Ovid PsycINFO 1987-, EBSCOhost CINAHL, SocINDEX, CSA Sociological Abstracts, Web of Science: Science Citation Index and Social Sciences Citation Index, and Scopus.

The scientific grey literature were also searched using GreySource: A Selection Of Web-Based Resources in Grey Literature, ProQuest Dissertations and Theses, and ProQuest Dissertations and Theses - UK & Ireland, Conference Proceedings Citation Index, and the Virginia Henderson International Nursing Library. The significant influence of the grey literature on the SR results has been shown in several studies (Hopewell, McDonald, Clarke, & Egger, 2007; McAuley, Pham, Tugwell, & Moher, 2000; Conn, Valentine, Cooper, & Rantz, 2003). Hence, it was crucial to include grey literature as an important source. Theses provided a substantial amount of information, notably raw data in the form of participants' quotes, which may not be accessible in the published literature as a result of the word limits that often apply to publications (see Evangelista, 2000, pp. 42-45, 134-139).

Networking and manual searching through key journals and reference lists of the selected literature served as strategies to avoid overlooking relevant published and unpublished reports due to indexing errors or delays (Boynton, Glanville, McDaid, & Lefebvre, 1998). The search identified 10130 studies via databases and manual searches. After removing duplicates, 6467 articles were initially screened via title and abstract review for relevance to the research goals, resulting in the full-text review of 579 papers. Then, the full text of the publications was read to determine whether studies met the inclusion criteria. 525 articles were excluded because records were: abstract, reviews, meta-analysis, or systematic reviews, descriptive paper, another language, meeting exclusion criteria, duplicate, not relevant to patients' values and self-care, not relevant to HF population. Any disagreement between researchers over the study selection process and data extraction decisions were discussed until consensus was reached. Of these, 54 met the criteria for inclusion.

The data from all included studies were extracted according to a data extraction form which has been developed by Alexander M. Clark; in order to follow a certain protocol, to ensure that the process was repeatable, and to address the dependability of the study (Appendix II). The quality of the studies was assessed using the appropriate mixed-methods appraisal tool (MMAT), which assessed the methodological quality of quantitative, qualitative and mixed-methods studies (Pluye et al., 2011). The content validity and the reliability of the MMAT have been examined (Pluye et al., 2011). The weaknesses and strengths of the studies was identified using this tool and accordingly the studies were ranked at high, medium, and low-quality levels. Low quality studies are those with more weaknesses than strengths and are characterized by "data [that are] too invariable, due to inadequate analysis or sampling strategy [.] [The] data do not *ring true* and it appears that the authors had super- imposed their own set of idea[s]" (MacEachen et al., 2006, p. 259). These were excluded because these results may have the potential to misled our understanding (Dixon-Woods, 2007; Moher, 1998).

Similarly, this step was undertaken for the quantitative studies but the process of qualitizing the data was added. In doing so, the data were obtained from the results and the discussion sections in quantitative studies and converted into the qualitative data (qualitizing data) (Creswell & Clark, 2010; Sandelowski et al., 2006; Tashakkori & Teddlie, 2010). This was based on the notion that "quantitative information rests upon qualitative judgment" (Kane & Trochim, 2007, p. 177). These data as well as the results of open-ended questions were integrated with data from qualitative studies (Andrew & Halcomb, 2009; Sandelowski et al., 2006).

Qualitizing data. As mentioned earlier, the qualitizing technique, which translates quantitative data into qualitative data, enabled me to conduct a meta-ethnography as a means of synthesising qualitative research. In doing so, four types of profiles were applied concurrently as follows:

- *Modal profile.* Based on this profile, a narrative description of the most frequently occurring characteristics of participants (Taskkori &Teddlie, 1998; Teddlie &Tashakkori, 2008), such as age, sex, and severity of HF disease, was provided (e.g. members of the 70- to 80-year-old group was described as *elderly individuals*).

- *Average profile.* This form of narrative description was applied by focusing on the average of the particular variables (i.e., the mean)(Taskkori &Teddlie, 1998; Teddlie &Tashakkori, 2008). This approach to qualitizing the quantitative data was common in quantitative papers in which authors attempt to interpret research results. For instance, in a descriptive correlational study (Artinian, Magnan, Sloan, & Lange, 2002), the authors interpret a quantitative finding, "there was a significant relationship between the mean total knowledge score and the total mean self-care score ($r = 0.21$, $P = .026$)" (p.161), with another narrative statement: "knowledge [is] related to self-care [in HF patients]" (p. 171). These types of narrative description in the literature were considered to be average profiles.
- *Comparative profile.* This narrative description was built on a comparison of key outcomes (Taskkori &Teddlie, 1998; Teddlie &Tashakkori, 2008), such as the scores achieved by two groups related to a variable. Accordingly, a finding that "the traditional remedy belief score was significantly higher among patients who had a positive family history of diabetes mellitus ($P < 0.001$)" was qualitized as follows: "patients with a family history of diabetes believe in traditional remedies."
- *Holistic profile.* This type of qualitizing was applied to provide overall impressions based on a combination of the modal, average, and comparative profiles (Taskkori &Teddlie, 1998; Teddlie &Tashakkori, 2008) (Taskkori

> &Teddlie, 1998; Teddlie &Tashakkori, 2008). For instance, a finding that “there was a negative correlation between relogicity and treatment adherence (r = −0. 15, p = 0.041 in patients 60-80 years” were qualitized as follows: “elderly patients’ religious beliefs relate to treatment non-adherence.”

As such, these types of profiles provided a deeper understanding of the phenomena (Johnson & Christensen, 2012). This understanding was further optimized by developing critical questions, which facilitated the investigation of the influence of patients’ values on their self-care decision-making from two types of data.

Phase 3: Reading the studies and determining how the studies are related. Given the hypothesis of meta-ethnography – that “this approach is the synthesis of texts” and “the synthesis is more dynamic and develops throughout the synthesis effort” (Noblit & Hare, 1988)– the analysis began with the process of reading the included studies by focusing attention on the details related to HF patients’ values and self-care decision-making. In the process of reading and re-reading the accounts, attempts were made to identify all interpretive metaphors, themes, concepts, and quotes that are explicitly or implicitly related to these values. For example, data related to HF patients’ values may be buried in an article that focuses on HF patients’ beliefs. The meta-ethnography approach, which was based on translating the findings from each individual study into those of the others, facilitated this process.

In translating these findings, it was essential to re-read articles carefully to understand the contexts, aims, and applied approaches, theories, and pre-assumptions underpinning the various studies. This may reveal, as Noblit and Hare (1988) showed, that two studies with opposing results have different pre-assumptions. They then came to the conclusion that such refutational studies might be complementary.

The key metaphors, phrases, ideas, and/or concepts (and their relations), were then compared with each other. This allowed me to make an initial assumption about whether the relationship between studies was reciprocal (studies are about similar things), refutational (studies refute each other), and/or involves “lines-of-argument” (studies suggest a line-of-argument) about patients’ values and the impact of values on self-care decision-making in HF patients. These assumptions guided me in applying the appropriate approach to the translation and synthesis of the data. The use of all three of these methods of meta-ethnography was based on the assumption, that central to the work of Dixon-Woods et al. (2005) and Campbell et al. (2011), that one meta-ethnography may include all three different types of synthesis. Subsequently, the implied line of argument, reciprocal and reputational translation, were analyzed and then were incorporated into the synthesis of inferences. This method, likewise, was used for qualitized data.

Phase 4: Translating the studies into one another and synthesizing translations. This step was started after arranging all articles based on two criteria: first, the level of relatedness to the main aim of this study, and second, their quality ranking scale on the extraction sheet (Appendix J). Then, the studies were translated into each other according to the hypothesis established in the previous step (Noblit & Hare, 1988).

For example, if studies focus on both similar and different themes, the synthesis takes the form of reciprocal translations and/or refutational translations (Noblit & Hare, 1988). To do so, the major concepts, themes, and/or quotes relevant to the patients’ value from the perspectives of patients, informal caregivers, and health care professionals were identified. Those major findings were examined; values were identified and labeled based on the definitions of 19 values in the Refined Theory of Basic Individual Values (Appendix L) (Schwartz et al., 2012). Those findings (the major themes and the labeled values) were compared with those in other studies. For example, a recent quantitative study found a lack of association between HF beliefs and self-care (Albert et al., 2013). If this result was refuted, re-reading the opposing studies was essential in order to understand the context, aims, and applied approaches, theories, and presumptions underpinning those studies. As discussed previously, Noblit and Hare (1988) showed that two refuting studies had different pre-assumptions and concluded that refuting studies were actually complementary.

This process was also used for qualitized data. The qualitative and quantitative-driven procedures provided the most appropriate quotes or themes, or proposed a new theme if there was no appropriate theme (Noblit and Hare, 1988). This process provided an opportunity to identify a list of value priorities for HF patients based on the frequency of each value across studies. New values that were related to the specific context of HF were identified for HF patients. This translating process also allowed insights into how values impact self-care decision-making. Studies that make an argument about values and self-care in HF patients were understood in terms of the third assumption (the lines-of-argument synthesis). These studies were translated into one another. This approach as a type of grounded theorizing was applied by conducting repeated comparisons between studies to identify analogous and dissimilar inferences between studies. However, in order to develop a theory from qualitative and qualitized data, these two sources of inferences need to be integrated (Cresswell, 2013).

Integration of qualitative and qualitized-driven inferences for comparative and pattern analysis. Integration in a mixed methods study means the process of “making meaningful conclusions on the basis of consistent or inconsistent results” (Teddlie & Tashakkori, 2009, p. 305). The integration of data was managed by using a matrix tool (Table J.1) as a visual display and a more practical strategy to facilitate exploring the pattern of relationship between the inferences derived from two groups of studies (Andrew & Halcomb, 2009; Tashakkori & Teddlie, 2010). The matrix included columns for qualitative, qualitized, and integrated inferences as well as patterns. Data on each row was the inferences that were developed through meta-ethnography methods. The inferences for each group was placed with transformation of particular data (e.g. data related to age, gender, severity of disease, and etc.). On occasion some of the blocks in the matrix may be empty, when there was no data from qualitative or qualitized sources of data on a particular theme. The extracted themes were compared between two sources using constant comparison analysis to reveal any patterns (Creswell, 2013). This process allowed development of a theory of the impact of values on self-care decision-making, via understanding hidden meanings that present a "picture of the whole."

Table J.1

Matrix of Inferences

	Qualitative	Qualitized	Integrated Inferences	Patterns
Inference #1				
Inference #2				
Inference #3				
Inference #4				
Inference #5				
Inference #6				
Inference #7				

The quality of the inferences. The quality of the inferences and meta-inferences (resulting from the integration of inferences) in this study was maintained by applying the *integrative framework* developed by Tashakkori and Teddlie (2006, 2008). In particular, this framework focuses on mixed methods studies, and provides detailed common sets of standards (Teddlie &Tashakkori, 2009) based on two quality aspects: a) quality of design and b) interpretive rigor (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009).

This study met design quality requirements for the following four key reasons:

1) *Design appropriateness* (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009). As discussed earlier, a mixed methods approach was chosen as the most suitable and appropriate design for this second study. It allowed me to synthesize data from different studies with different applied methodologies that may provide complementary data and clarify different aspects of the complexity. This deepened my understanding of how HF patients' decisions regarding self-care are influenced by values. Implementing the monostrand method also allowed me to convert all data from quantitative studies that address the same question into the qualitative format. This also allowed me to apply a meta-ethnography approach. The integration of meta-ethnography into the monostrand mixed method approach enabled me to rigorously capture the meanings of, and relationships between, themes and inferences.

2) *Design adequacy* (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009). To achieve this aim, this systematic review adhered to the particular protocol (Schlosser, 2007) explained in the methods section, which involves the methods for searching and screening the literature (based on inclusion criteria), extracting data, assessing quality, and synthesizing data. The comprehensive search method enabled me to minimize bias in selection of primary studies. This step was also followed by the application of the MMAT appraisal checklists to select qualified studies (Appendix J). The appraisal strategy was also completed by using the extraction data sheet to seek information regarding sampling, data collection, and methods, allowing me to

assess whether sampling and data collection were implemented adequately in a given study. For example, we identified whether there was a fit between the length of a focus group session and the number of participants or whether prolonged engagement was well established in an ethnographic study (Teddlie & Tashakkori, 2009); accordingly, the study was ranked in terms of quality.

3) *Design consistency.* At the same time, these tools allowed examination of whether the design components fit together (Teddlie & Tashakkori, 2009, 2010), for example, whether an applied model or questionnaire in a study has cross-cultural applications. The results were reflected on the extraction form as weaknesses or strengths, and impacted the ranking process for each study.

4) *Analytic adequacy* (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009). Applying the meta-ethnographic method provided a systematic method to determine the relationship between the studies (the second-level inference) and to develop a new interpretation (the third-level inference).

Interpretive rigor (credible interpretations) was also important to establish based on the following:

1. Interpretive consistency (consistency between findings and inferences) (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009) was ensured by proving sufficient supportive evidence to support the process of making inferences in an audit trail (Guba, 1981; Guba & Lincoln, 1982).

2. Credible explanation (consistency between inferences and current knowledge) (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009) for each inference was provided, and was supported by theoretical knowledge and research-based evidence.

3. Interpretive agreement (agreement about a decision among researchers) (Tashakkori & Teddlie, 2010; Teddlie &Tashakkori, 2009) was reached for all steps, such as qualitizing data and drawing inferences, by seeking feedback from my supervisor, who has extensive knowledge and background in conducting and teaching systematic review studies.

4. Interpretive distinctiveness (the difference of the conclusion from other possible credible conclusions) was first achieved by explaining why other possible inferences and interpretations are refuted. This step was also used for qualitizing data to describe how the qualitized data can capture insights from quantitative data. Second, reflexivity was also addressed in a reflexive journal. Given that I have a chronic disease and I have to maintain lifelong adherence, according to Ahern (1999), I tried to clarify my personal values and feelings that may impact my neutrality before starting the study and for all decision-making processes regarding inferences. In writing up the findings of this study, I reflected on the literature to support my findings. This allowed me to ensure that the results are based on the raw data to reflect the truth (Creswell, 2002), and not our assumptions.

5. Integrative efficacy is “the degree to which inferences made in each strand of an MM study are effectively integrated into a theoretically consistent meta-inference, …” (Teddlie & Tashakkori, 2009, p. 305). This was achieved by following protocols designed and mapped by applying different strategies including modal, average, comparative, and holistic profiles to convert quantitative data into qualitative data. Then three types of meta-ethnographic synthesis methods, including reciprocal, refutational, and/or lines of argument were employed for each strand (qualitative data and qualitized data) of this study. These methods helped me to uncover and analyze different relations between results of the studies. For example, as was discussed earlier, the refutational method may provide divergent inferences that may be rooted in different

theories. Such a method of investigating refutational inferences may lead me to understand this phenomenon in-depth (by analyzing the refutational studies to understand why these results are or appear to be divergent) rather than jumping to the conclusion that some of the findings are simply inconsistent. All of these approaches allowed me to obtain and compare all relative data, to investigate the consistency and inconsistency among inferences in-depth, and to generate valid meta- inferences.

Appendix L: Basic Individual Values

The 19 Values with Definitions in the Refined Theory of Basic Individual Values– Adapted from Adapted from Refining the theory of basic individual values (2012) by Schwartz et al, Journal of Personality and Social Psychology, 103(4).

Value	Conceptual definitions in terms of motivational goals
Self-direction–thought	Freedom to cultivate one's own ideas and abilities
Self-direction–action	Freedom to determine one's own actions
Stimulation	Excitement, novelty, and change
Hedonism	Pleasure and sensuous gratification
Achievement	Success according to social standards
Power–dominance	Power through exercising control over people
Power–resources	Power through control of material and social resources
Face	Security and power through maintaining one's public image and avoiding humiliation
Security–personal	Safety in one's immediate environment
Security–societal	Safety and stability in the wider society
Tradition	Maintaining and preserving cultural, family, or religious traditions
Conformity–rules	Compliance with rules, laws, and formal obligations
Conformity–interpersonal	Avoidance of upsetting or harming other people
Humility	Recognizing one's insignificance in the larger scheme of things
Benevolence–dependability	Being a reliable and trustworthy member of the in-group
Benevolence–caring	Devotion to the welfare of in-group members
Universalism–concern	Commitment to equality, justice, and protection for all people
Universalism–nature	Preservation of the natural environment
Universalism–tolerance	Acceptance and understanding of those who are different from oneself

Appendix M: Search strategies

Supplementary File 1

Search strategies

Platform	**Database**	**Date Search Run**	**# of Citations Retrieved**
Ovid	MEDLINE In-Process & Other Non-Indexed Citations	14 March 2014	79
	MEDLINE 1946-	14 March 2014	1558
	Embase 1996-	14 March 2014	2636
	PsycINFO 1987-	14 March 2014	727
EBSCOhost	CINAHL	14 March 2014	2404
	SocINDEX	14 March 2014	326
CSA	Sociological Abstracts	14 March 2014	64
Web of Science		14 March 2014	1055
Elsevier	Scopus	14 March 2014	1275
		Sub-Total	10124
		Duplicates	
		# of Citations Reviewed	

DATABASES

MEDLINE 1946- & MEDLINE In Process

1. heart failure/ or dyspnea, paroxysmal/ or edema, cardiac/ or heart failure, diastolic/ or heart failure, systolic/
2. (heart failure or cardiac failure or heart decompensation or cardic edema or cardia oedema or congestive heart).tw.
3. (HF or CHF).ti.
4. or/1-3
5. self-care/
6. 4 and 5
7. self medication/ or risk reduction behavior/ or disease management/
8. (self adj3 (manag* or care or administ* or monitor* or efficac* or medicat* or mainten* or regulat* or treat*)).ti,ab.
9. disease manag*.tw.
10. exp Exercise/
11. exp Exercise Therapy/
12. Physical Fitness/
13. (physical adj (fitness or activit*)).tw.
14. (exercise adj (training or program*)).tw.
15. (exercise adj (training or program* or therap*)).tw.
16. exp Diet/
17. (diet* adj3 modif*).tw.
18. (low* adj (sodium orsalt)).tw.
19. Fluid Therapy/
20. (fluid adj (therapy or restrict* or intake)).tw.
21. smok*.tw. or "tobacco use cessation"/ or smoking cessation/

22. exp diuretics/ or exp angiotensin-converting enzyme inhibitors/ or exp antihypertensive agents/ or exp adrenergic beta-antagonists/ or exp vasodilator agents/
23. or/7-22
24. 4 and 23
25. ((patient or participant*) adj3 (value* or perception* or belief* or barrier* or obstacl* or priorit* or choice* or preference* or wish* or feeling* or trust* or distrust*)).tw.
26. px.fs.
27. Patient-Centered Care/ or Trust/
28. or/25-27
29. 24 and 28
30. attitude to health/ or health knowledge, attitudes, practice/ or "patient acceptance of health care"/ or patient compliance/ or medication adherence/ or "patient acceptance of health care"/ or patient participation/ or Refusal to Participate/
31. (patient* adj3 (complian* or comply or complies or co operat* or cooperat* or concordance or adher*)).tw.
32. (noncomplian* or non complian* or nonparticipa* or nonadherence or non-participa* or non-adherence).tw.
33. intention/ or decision making/ or choice behavior/ or Treatment Refusal/ or Patient Dropouts/
34. Health Behavior/
35. or/30-34
36. 4 and 35
37. exp qualitative research/
38. exp Nursing Methodology Research/
39. anthropology, cultural/
40. exp focus groups/
41. qualitative.mp.
42. (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).mp.
43. (leininger$ or noblit).mp. or hare.ti,ab.
44. (field note$ or field record$ or fieldnote$ or field stud$).mp.
45. (participant$ adj3 observ$).mp.
46. (nonparticipant$ adj3 observ$).mp.
47. (non participant$ adj3 observ$).mp.
48. (hermeneutic$ or phenomenolog$ or lived experience$).mp.
49. (heidegger$ or husserl$ or merleau-pont$).mp.
50. (colaizzi$ or giorgi$).mp.
51. (ricoeur or spiegelberg$).mp.
52. (van kaam$ or van manen).mp.
53. (Grounded adj5 theor$).mp.
54. (constant compar$ or theoretical sampl$ or triangulat$).ti,ab.
55. (glaser and strauss).mp.
56. (content analys$ or thematic analys$ or narrative analys$).mp.
57. (unstructured categor$ or structured categor$).mp.
58. (unstructured interview$ or semi-structured interview$ or semistructured interview$).mp.
59. (maximum variation or snowball).mp.
60. (audiorecord$ or taperecord$ or videorecord$ or videotap$).mp.
61. ((audio or tape or video$) adj5 record$).mp.
62. ((audio$ or video$ or tape$) adj5 interview$).mp.
63. (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).ti,ab.
64. (meta-ethnog$ or metaethnog$ or meta-narrat$ or metanarrat$ or meta-interpret$ or metainterpret$).mp.
65. (qualitative adj5 meta-analy$).mp.
66. (qualitative adj5 metaanaly$).mp.

File 1 *(continued)*

67. purposive sampl$.mp.
68. action research.mp.
69. focus group$.mp.
70. (exp interview/ or exp interview as topic/) and px.fs.
71. (theme*.ti,ab. or experience*.ti. or audio*.ti,ab. or video*.ti,ab. or recording.ti,ab. or exp Tape Recording/ or exp Video Recording/) and px.fs.
72. (experience*.ti. or theme*.ti,ab.) and ((audio* or video* or recording).ti,ab. or exp Tape Recording/ or exp Video Recording/)
73. interview*.ti,ab. and (views or perception* or belief* or attitude* or barrier* or facilitat* or perspective*).mp.
74. (photo voice or photovoice).mp.
75. or/37-74
76. 4 and 75
77. (mixed method* or multi-method* or multiple research method* or multiple method* or multimethod* or mixed model* or mixed research).tw.
78. ((qualitative or qual) and (quantitative or quan) and (nested or blend* or concurrent or complementary or expansion or initiation or holistic or transformative or embedded or iterative or triangulat*)).tw.
79. ((quantitative or quan) and (phenomenolog* or ethno* or (grounded adj3 theor*) or hermeneutic* or lived experience* or content analys* or thematic or theme* or narrative* or interview* or focus group* or action research)).tw.
80. (triangulat* adj15 (method* or data or concurrent or sequential or simultaneous or design*)).tw.
81. (qualitative adj5 quantitative adj5 (combin* or mixed or mix or integrat* or method* or analys*)).tw.
82. exp qualitative research/ and quantitative.tw.
83. or/77-82
84. (qualitative and quantitative).tw.
85. exp Nursing Research/ or exp Health Services Research/ or exp Rehabilitation/
86. (px or nu or rh or ed or og or es or eh).fs.
87. (nurs* or educat* or rehabilitat* or psych* or social or socio* or service* or interview* or questionnaire* or survey*).af.
88. or/85-87
89. 84 and 88
90. 83 or 89
91. (clinical trial* or evaluation studies or randomized controlled trial).pt.
92. (randomized or (clinical adj3 trial*) or (controlled adj3 trial*)).mp.
93. 91 or 92
94. qualitative.mp.
95. 93 and 94
96. ((qualitative or quantitative) adj5 nested).tw.
97. 90 or 95 or 96
98. 4 and 97
99. 6 or 29 or 76 or 98
100. limit 99 to (english language and yr="2000 -Current")

Embase

1. *heart failure/ or *acute heart failure/ or exp *congestive heart failure/
2. (heart failure* or cardiac failure* or heart decompensation or cardiac edema* or cardiac oedema* or congestive heart).tw.
3. (CHF or HF).ti.
4. or/1-3
5. self-care/
6. 4 and 5

7. *health behavior/ or *attitude to health/ or *health belief/ or *patient attitude/ or *patient compliance/ or *patient participation/ or *refusal to participate/ or *treatment refusal/ or *decision making/ or *self medication/ or *self help/ or *harm reduction/ or *risk reduction/
8. (self adj3 (manag* or care or administ* or monitor* or efficac* or medicat* or mainten* or regulat* or treat* or adher*)).ti.
9. (patient* adj3 (complian* or comply or complies or co operat* or cooperat* or concordance or adher*)).ti.
10. (noncomplian* or non complian* or nonparticipa* or non-participa* or nonadher* or non-adher*).ti.
11. or/7-10
12. 4 and 11
13. disease management/ or exp exercise/ or exp physical activity/ or fitness/ or drinking behavior/ or smoking cessation/ or exp diuretic agent/ or fluid therapy/
14. (physical adj (fitness or activit*)).tw.
15. (exercise training or exercise program*).tw.
16. (health* adj eat*).tw.
17. (diet* adj modif*).tw.
18. (low* adj (sodium or salt)).tw.
19. (fluid adj (therapy or restrict* or intake)).tw.
20. smok*.tw.
21. diuretic*.tw.
22. or/13-21
23. (patient adj3 (value* or perception* or belief* or barrier* or obstacl* or priorit* or choice* or preference* or wish* or feeling*)).tw.
24. (patient adj (center* or centre*)).mp.
25. exp behavioral science/
26. 4 and 22 and 25
27. qualitative.mp.
28. (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).mp.
29. (leininger$ or noblit or hare).ti,ab.
30. (field note$ or field record$ or fieldnote$ or field stud$).mp.
31. (participant$ adj3 observ$).mp.
32. (nonparticipant$ adj3 observ$).mp.
33. (non participant$ adj3 observ$).mp.
34. (hermeneutic$ or phenomenolog$ or lived experience$).mp.
35. (heidegger$ or husserl$ or merleau-pont$).mp.
36. (colaizzi$ or giorgi$).mp.
37. (ricoeur or spiegelberg$).mp.
38. (van kaam$ or van manen).mp.
39. (Grounded adj5 theor$).mp.
40. (constant compar$ or theoretical sampl$ or triangulat$).ti,ab.
41. (glaser and strauss).mp.
42. (content analys$ or thematic analys$ or narrative analys$).mp.
43. (unstructured categor$ or structured categor$).mp.
44. (unstructured interview$ or semi-structured interview$ or semistructured interview$).mp.
45. (maximum variation or snowball).mp.
46. (audiorecord$ or taperecord$ or videorecord$ or videotap$).mp.
47. ((audio or tape or video$) adj5 record$).mp.
48. ((audio$ or video$ or tape$) adj5 interview$).mp.
49. (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).ti,ab.
50. (meta-ethnog$ or metaethnog$ or meta-narrat$ or metanarrat$ or meta-interpret$ or metainterpret$).mp.

File 1 (*continued*)

51. (qualitative adj5 meta-analy$).mp.
52. (qualitative adj5 metaanaly$).mp.
53. purposive sampl$.mp.
54. action research.mp.
55. focus group$.mp.
56. (photo voice or photovoice).mp.
57. or/27-56
58. 4 and 57
59. (mixed method* or multi-method* or multiple method* or multiple research method* or multimethod* or mixed model* or mixed research).tw.
60. ((qualitative or qual) and (quantitative or quan) and (nested or concurrent or complementary or expansion or initiation or holistic or transformative or embedded or iterative or triangulat*)).tw.
61. ((quantitative or quan) and (phenomenolog* or ethno* or (grounded adj3 theor*) or hermeneutic* or lived experience* or content analys* or thematic or theme* or narrative* or interview* or focus group* or action research)).tw.
62. (triangulat* adj15 (method* or data or concurrent or sequential or simultaneous or design*)).tw.
63. (qualitative adj5 quantitative adj5 (combin* or blend* or mixed or mix or integrat* or method* or analys*)).tw.
64. exp qualitative research/ and quantitative.tw.
65. or/59-64
66. (qualitative and quantitative).tw.
67. (nurs* or educat* or rehabilitat* or psych* or social or socio* or service* or interview* or questionaire* or survey*).af.
68. 66 and 67
69. 65 or 68
70. (qualitative and (randomized or (clinical adj3 trial*) or (controlled adj3 trial*))).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
71. ((qualitative or quantitative) adj5 nested).tw.
72. 69 or 70 or 71
73. 4 and 72
74. 6 or 12 or 26 or 58 or 73
75. limit 74 to (english language and yr="2000 -Current")
76. remove duplicates from 75

PsycINFO

1. (heart failure* or cardiac failure* or heart decompensation or cardiac edema* or cardiac oedema* or CHF or HF or congestive heart).mp.
2. Health Attitudes/ or self-care Skills/ or Self Management/ or health knowledge/ or client attitudes/ or treatment barriers/ or treatment compliance/ or treatment dropouts/ or lifestyle changes/ or "physical illness (attitudes toward)"/ or health behavior/ or self referral/ or help seeking behavior/ or health care seeking behavior/ or intention/ or motivation/ or decision making/ or choice behavior/
3. (self adj3 (manag* or care or administ* or monitor* or efficac* or treat* or medicat* or adher*)).mp.
4. disease manag*.mp.
5. (patient* adj (complian* or comply or complies or co operat* or cooperat* or concordance or adher*)).mp.
6. (noncomplian* or non complian* or nonparticipat* or non-participat* or nonadher* or non-adher*).mp.
7. exp exercise/ or physical activity/ or movement therapy/ or physical fitness/ or active living/
8. (physical adj (fitness or activit*)).mp.
9. (exercise training or exercise program*).mp.
10. diets/ or dietary restraint/ or alcohol drinking patterns/ or drinking behavior/
11. (diet* adj3 modif*).mp.
12. (low* adj (sodium or salt)).mp.
13. (health* adj eat*).mp.
14. (fluid adj (therapy or restrict* or intake)).mp.

15. alcohol*.mp.
16. smoking cessation/
17. smok*.mp.
18. diuretics/ or acetazolamide/ or caffeine/ or theophylline/
19. diuretic*.mp.
20. or/2-19
21. 1 and 20
22. limit 21 to (human and english language and yr="2000 -Current")

File 1 *(continued)*

CINAHL

S1 (MH "Heart Failure") OR (MH "Dyspnea, Paroxysmal")
S2 ("heart failure" or "cardiac failure" or "heart decompensation" or "cardiac edema" or "cardiac oedema" or "congestive heart") OR TI (CHF or HF)
S3 S1 OR S2
S4 (MH " self-care")
S5 (MH "Disease Management")
S6 (MH "Self Medication") OR ((MH "Attitude to Health") OR (MH "Health Beliefs") OR (MH "Patient Compliance") OR (MH "Medication Compliance") OR (MH "Attitude to Illness") OR (MH "Treatment Refusal") OR (MH "Attitude to Risk")) OR (MH "Patient Satisfaction") OR ((MH "Intention") OR (MH "Decision Making") OR (MH "Decision Making, Patient"))
S7 self N3 manag* or self N3 care or self N3 administ* or self N3 monitor* or self N3 efficac*
S8 "disease manag*" or "decision making"
S9 patient* N1 complian* or patient* N1 comply
S10 patient* N1 complies or patient* N1 adher*
S11 patient* N1 co-operat*
S12 patient* N1 cooperat* or patient* N1 concordance
S13 (noncomplian* or nonparticipa* or nonadherence) or (non-complian* or non-participat* or non-adherence)
S14 S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
S15 S3 AND S14
S16 S3 AND S14
S17 ((MH "Physical Fitness") OR (MH "Exercise+")) OR (MH "Diet+") OR (MH "Fluid Therapy") OR (MH "Diuretics+") OR ((MH "Alcohol Drinking") OR (MH "Drinking Behavior") OR (MH "Smoking")) OR (MH "Smoking Cessation")
S18 (physical N1 fitness or physical N1 activit*) OR exercise* OR (fluid N1 therapy or fluid N1 restrict* or fluid N1 intake) OR (smok* OR tobacco)
S19 S17 OR S18
S20 S3 AND S19
S21 (patient* N3 (value* or perception* or belief* or barrier* or obstacl* or priorit* or choice* or preference* or wish* or feeling* or trust* or distrust*)) OR (participant* N3 (value* or perception* or belief* or barrier* or obstacl* or priorit* or choice* or preference* or wish* or feeling* or trust* or distrust*))
S22 (MH "Patient Centered Care")
S23 MW "pf"
S24 S21 OR S22 OR S23
S25 S20 AND S24
S26 ((MH "Qualitative Studies+" or qualitative OR ethnol* OR ethnog* OR ethnonurs* OR emic OR etic OR leininger OR noblit OR field note* OR field record* OR fieldnote* OR field stud* participant observ* OR participant observation* OR hermaneutic* OR phenomenolog* OR lived experience* OR heidegger* OR husserl* OR merleau-pont* OR colaizzi OR giorgi OR ricoeur OR spiegelberg OR van kaam OR van manen OR grounded theory OR constant compar* OR theoretical sampl* OR glaser AND strauss OR content analy* OR thematic analy* OR narrative* OR unstructured categor* OR structured categor* OR unstructured interview* OR semi-structured interview* OR maximum variation* OR snowball OR audio* OR tape* OR video* OR metasynthes* OR meta-synthes* OR metasummar* OR meta-summar* OR metastud* OR meta-stud* OR meta-ethnograph* OR metaethnog* OR meta-narrative* OR metanarrat* OR meta-interpretation* OR metainterpret* OR qualitative meta-analy* OR qualitative metaanaly* OR qualitative metanaly* OR purposive sampl* OR action research OR focus group*))
S27 S3 AND S26
S28 ((mixed method* or multi-method* or multimethod* or mixed model* or multiple method* or mixed research) or (MH "Qualitative Studies+" and MH "Quantitative Studies") or (MH Triangulation or method* n3 triangulat* or concurrent n3 triangulat* or triangulat* n3 data or triangulat* n3 sequential or triangulat* n3

simultaneous) or ((phenomenolog* or ethno* or grounded n3 theor* or hermeneutic* or lived experience* or content analys* or thematic or theme* or narrative* or interview* or action research) and quantitative) or (qualitative and quantitative) or (qualitative n5 nested or quantitative n5 nested) or qualitative and (randomized or clinical n5 trial* or controlled n5 trial*))

S29 S3 AND S28
S30 S16 OR S25 OR S27 OR S29
S31 S16 OR S25 OR S27 OR S29
S32 S16 OR S25 OR S27 OR S29
Limiters - English Language; Published Date: 20000101-20141231; Research Article

SocINDEX

S1 "heart failure" OR "congestive heart" or "cardiac failure"
Scholarly (Peer Reviewed) Journals; Date of Publication: 20000101-20141231; Language: English

Sociological Abstracts

"heart failure" or "cardiac failure" or "heart decompensation" or "cardic edema" or "cardia oedema" or "congestive heart"
Searched in the anywhere field. 2000-2014 English only

Web of Science: Science Citation Index & Social Sciences Citation Index

#3 #1 AND #2
#2 TOPIC: ("self manag*" or " self-care" or "self administr*" or "self monitor*" or "self efficac*" or "self medicat*" or "self mainten*" or "self regulat*" or "self treat*")
#1 TOPIC: ("heart failure" or "cardiac failure" or "heart decompensation" or "cardic edema" or "cardia oedema" or "congestive heart")
Indexes=SCI-EXPANDED, SSCI Timespan=2000-2014
Refined by: LANGUAGES=(ENGLISH)

Scopus

(TITLE-ABS-KEY("self manag*" OR " self-care" OR "self administr*" OR "self monitor*" OR "self efficac*" OR "self medicat*" OR "self mainten*" OR "self regulat*" OR "self treat*")) AND (TITLE-ABS-KEY("heart failure" OR "cardiac failure" OR "heart decompensation" OR "cardic edema" OR "cardia oedema" OR "congestive heart") AND PUBYEAR > 1999) AND (LIMIT-TO(LANGUAGE, "English"))

Appendix N: Supplementary File 2

Summary of themes identified in studies included in the review

	Underlying mechanisms		Key processes											
	Prioritizing values	Blocking values	The impacts of HF on individuals' values priorities	The impact of value priorities on self-care										The impact of self-care on the pursuit of prioritized values
				Self-related values					Other-related values					
				Personal feelings			Life circumstances		Social benefits		Social obligations			
				Self-direction	Pleasure	Being healthy	Maintaining a stable lifestyle	Financial balance	Social recognition	Socialization	Responsibility	Maintenance of tradition	Obedience	
Ågård, 2004														
Artinian, 2002												✓		
Barnes, 2006	✓			✓						✓	✓	✓		✓
Bennett, 2000					✓	✓				✓				✓
Bennett, 2005	✓		✓		✓									✓
Bentley, 2005	✓	✓			✓					✓		✓		
Black, 2006	✓													
Boren, 2001			✓	✓	✓	✓	✓			✓				✓
Bosworth, 2004			✓	✓							✓			
Cholowski, 2007												✓		
Clark, 2009	✓				✓						✓			
Conard, 2006	✓					✓		✓						
Cortis, 2007	✓								✓					
Crowder, 2005			✓	✓		✓		✓						

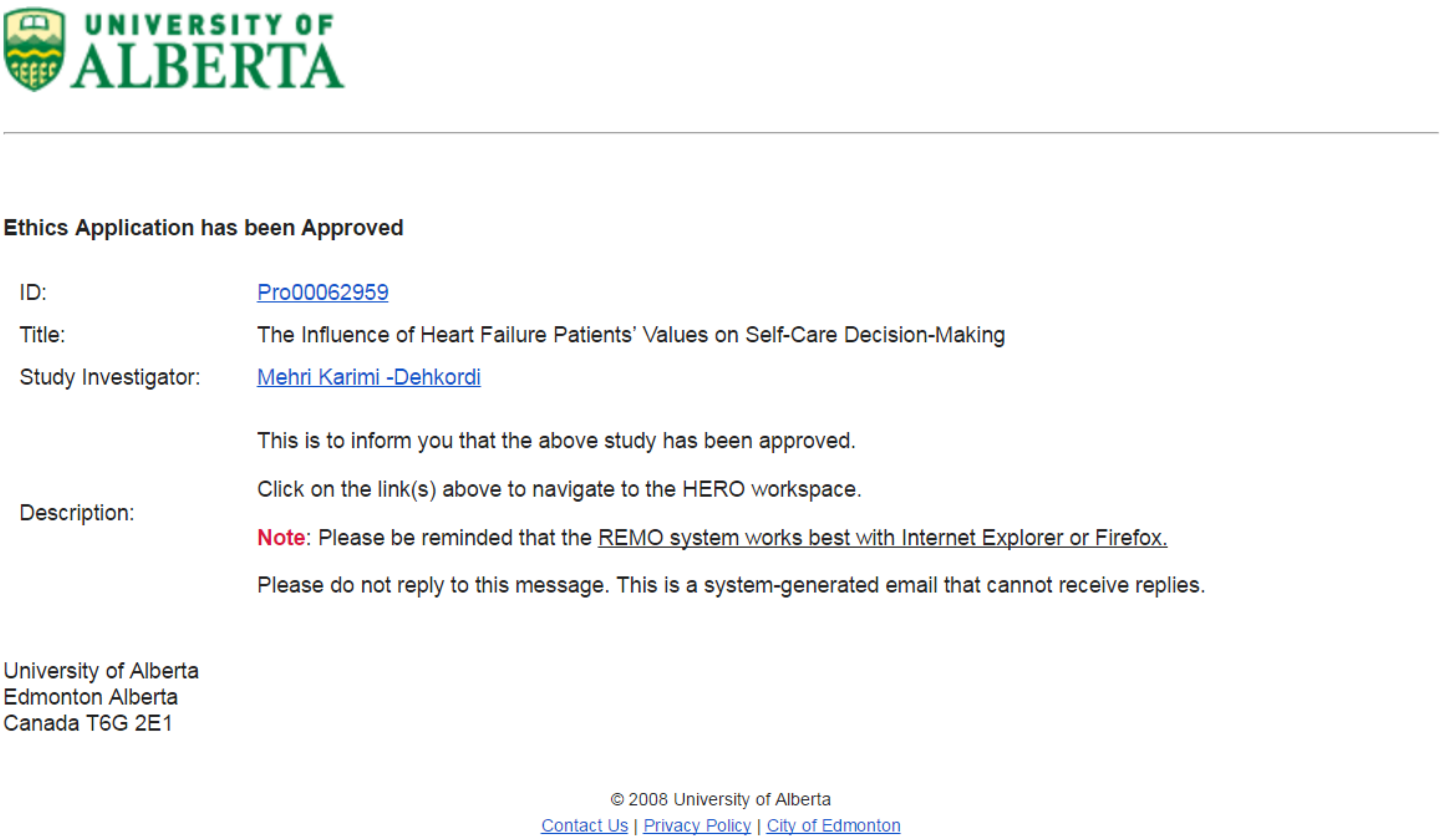
File 2 (*continued*)	**Underlying mechanisms**		**Key processes**											
	Prioritizing values	Blocking values	The impacts of HF on individuals' values priorities	The impact of value priorities on self-care										The impact of self-care on the pursuit of prioritized values
				Self-related values					Other-related values					
				Personal feelings			Life circumstances		Social benefits		Social obligations			
				Self-direction	Pleasure	Being healthy	Maintaining a stable lifestyle	Financial balance	Social recognition	Socialization	Responsibility	Maintenance of tradition	Obedience	
Darling, 2013								✓	✓	✓				
De Smedt, 2012				✓										
de Souza, 2011	✓	✓			✓									
Dickson, 2013									✓	✓		✓	✓	
Eldh, 2004				✓		✓			✓					
Evangelist, 2003				✓										
Evangelist, 2001	✓			✓				✓						
Farrell, 2011				✓	✓							✓	✓	
Freydberg, 2009											✓			
George, 2006											✓	✓		
Granger, 2013														✓
Heo, 2009a	✓			✓	✓	✓				✓			✓	✓
Heo, 2009b														
Hicks, 2003	✓							✓						
Hodges, 2009			✓			✓								
Imes, 2011			✓											
Jurgens, 2009								✓						
Kaholokul, 2007								✓	✓		✓	✓	✓	
Leeming, 2014	✓	✓				✓			✓	✓		✓		✓

File 2 (*continued*)

	Underlying mechanisms		**Key processes**											
	Prioritizing values	Blocking values	The impacts of HF on individuals' values priorities	The impact of value priorities on self-care										The impact of self-care on the pursuit of prioritized values
				Self-related values					Other-related values					
				Personal feelings			Life circumstances		Social benefits		Social obligations			
				Self-direction	Pleasure	Being healthy	Maintaining a stable lifestyle	Financial balance	Social recognition	Socialization	Responsibility	Maintenance of tradition	Obedience	
Lynga°, 2013											✓	✓		
Macabasco O'Conne, 2008								✓						
Mahoney, 2000	✓		✓	✓	✓					✓	✓	✓		
Matlock, 2010												✓	✓	
Molloy, 2009				✓										
Mooney, 2003				✓										
Pattende, 2007			✓	✓			✓	✓			✓	✓		
Rhodes, 2002					✓	✓			✓					
Rocha, 2009												✓		
Rodriguez, 2008							✓		✓					
Ryan, 2009			✓											
Scotto, 2003	✓	✓			✓		✓	✓	✓	✓	✓	✓	✓	
Scotto, 2003	✓	✓		✓			✓		✓					
Selman, 2007			✓											
Sethares, 2014						✓						✓	✓	
Simpson, 2000	✓				✓	✓				✓			✓	✓
Small et al., 2009			✓											
Stawnychy, 2014	✓					✓			✓		✓			

	Underlying mechanisms		**Key processes**											
	Prioritizing values	Blocking values	The impacts of HF on individuals' values priorities	The impact of value priorities on self-care										The impact of self-care on the pursuit of prioritized values
				Self-related values					Other-related values					
				Personal feelings			Life circumstances		Social benefits		Social obligations			
				Self-direction	Pleasure	Being healthy	Maintaining a stable lifestyle	Financial balance	Social recognition	Socialization	Responsibility	Maintenance of tradition	Obedience	
van der Wal, 2007					✓									
van der Wal, 2009					✓			✓		✓				
Whitty, 2012				✓					✓		✓			
Zambroski , 2003	✓	✓	✓			✓			✓	✓		✓		

Appendix O: Ethics Approval



UNIVERSITY OF ALBERTA

Ethics Application has been Approved

ID:	Pro00062959
Title:	The Influence of Heart Failure Patients' Values on Self-Care Decision-Making
Study Investigator:	Mehri Karimi -Dehkordi
Description:	This is to inform you that the above study has been approved. Click on the link(s) above to navigate to the HERO workspace. **Note**: Please be reminded that the REMO system works best with Internet Explorer or Firefox. Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

Appendix P: Recruitment Guide for Practitioners

University of Victoria
School of Nursing

island health

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

Research Study: Living with serious illness: Narratives of liminality
RECRUITMENT GUIDE FOR PRACTITIONERS
Heart Failure (HF)

This qualitative research study is focused on understanding the experiences of patients living with advanced disease and their families. We are interested in recruiting people with HF, who would be willing and able to discuss their experiences of living with illness, and who potentially have a family member who would also be willing to participate.

What the study is about …

The purpose of this study is to explore peoples' stories of living with advanced illness (both patients and family members/significant others). The study is funded by the Canadian Institutes of Health Research.

Why the study is important …

It is hoped that this study will contribute to health professionals' understanding of the complex processes people undergo when living with a life-limiting illness and how health care providers can better support patients and families experiencing the uncertainty of living with a advanced disease.

Who is eligible?

For people with HF we are looking for people who have been diagnosed with chronic heart failure (Stage II or III) according to the New York Heart Association classification. Potential participants may or *may not have* been referred to the palliative care clinic.

What are the inclusion and exclusion criteria?

Inclusion Criteria:

For people with HF we are looking for people who:

Are over 18 years of age [14]

Participants will have a heart failure diagnosis (preferably Class II or II as New York Heart Association (as patients commonly move back and forth between the two classes),

Participants are being followed in a heart function clinic within Island Health)

Within the past year have experienced exacerbations or complications or notable progression of disease;

May have one or more co-morbidities;

Are aware of their diagnosis (i.e. have been informed that they have heart failure);

Have a willingness to share their experiences of living with the uncertainties of serious illness;

Have the potential of having a family member who may also wish to participate in the study, however, this is not a requirement;

Have a willingness to be contacted by the researchers.

Exclusion Criteria:

Non-English speaking;

Any person with significant cognitive impairment that would impact their ability to share reflections about their experience of illness, or impact their capacity to provide informed consent;

Any person who is currently in acute distress related to their diagnosis.

Recruitment Considerations ...

If a person meets the inclusion criteria and would be willing to talk with the research team, please give them the Flyer. When we initiate contact with a potential participant, we will provide

---

[14] This criterion is related to a major CIHR study

them with information about the study and ask them if they have a family member/significant other who might also be willing to talk with us.

Rationale: Our previous research findings indicate that people living with life-threatening illness have varying perceptions of seriousness of illness, and their own risk of dying or mortality. Many think about death and their own mortality however at the same time focus on the hope of treatment and care. Potential participants will be told that investigators are interested in understanding what it is like to live with life-threatening illness and specifically HF. Interview questions will follow the cues and comments of the participants.

What participation involves …

Participation in three interviews (two in person and a telephone conversation) over approximately one year. The patient and family member will be invited to share how living with HF has influenced their experiences of living with the uncertainties of illness.

After the first interview, patients/family members will be given a digital camera so that they can take photographs of symbols, objects, or elements in their life that in some way represent living with the uncertainties of illness. Participants will be asked to take these photos before the second interview. They will be able to keep the camera, and the photos will be downloaded onto a photo-reader for us to analyze.

Ethical considerations:

Confidentiality will be respected. The study has obtained ethics approval from the Human Research Ethics boards at the University of Victoria, University of Alberta, Island Health, and the British Columbia Cancer Agency.

If a participant becomes fatigued during the interview, the interview will be stopped and continued at another mutually agreeable time.

Participants can withdraw from the study at any time.

Resources and supports will be available if the person experiences distress during the interviews.

There will be no impact on care, regardless of whether or not they participate.

There may be benefits in talking about experiences and topics related to living and dying that are typically not discussed with others.

Who are the researchers conducting the study …

Drs. Laurene Sheilds, RN, PhD (Principal Investigator), Anne Bruce, RN, PhD, Elizabeth Borycki, RN, PhD are faculty members at the University of Victoria and

Drs. Anita Molzahn, RN, PhD and Alex Clark, RN, PhD are faculty members at the University of Alberta, Faculty of Nursing; Kara Schick Makaroff RN, PHD is a Post-Doctoral Fellow, working with Dr. Molzahn at the University of Alberta Faculty of Nursing

Referring Participants?

If a person is interested in participating, please provide them with the Flyer and a member of the research team will contact them.

Contact information for the research team:

Marcy Antonio, Research Coordinator at 250-472-5371 email: story@uvic.ca

Appendix Q: Flyer

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

Living with Life-threatening Illness: Narratives of Liminality

We have an opportunity to participate in a study about the experiences of patients and their families living with Heart Failure.

What the study is about …

The purpose of this study is to hear peoples' stories of caring for someone who is living with serious illness. We want to understand how these experiences affect their lives. This study is funded by the Canadian Institute of Health Research.

Why the study is important …

Research of this type is important. We will share what we learn from this study with other health care workers. We hope that by hearing and understanding these stories, they will get better at helping patients and families when they are living with serious illness.

If you participate …

If you and your family member (or friend) would like to be involved, the researchers would like to talk with you both. Over the next year you will each take part in 3 interviews (2 in person and 1 by telephone). These interviews are not together. You both will be invited to share how a serious illness has influenced your experiences of living.

We will also ask you to take some photos of things that are important to you and describe how you feel, and to share those photos with us.

Protecting your rights …

Confidentiality is very important in research, and the researchers will carefully go over all parts of the study and consent process with you.

You may choose to withdraw (leave) the study at any time and for any reason.

What you will get out of the study …

You might find that talking with someone who is interested and educated in this area to be helpful. But you may not get any benefit from being in this study.

We do not expect you to experience any problems because of this study, but it is not possible to know all of the risks that may happen in a study.

Do you want to learn more about the study?

If you are interested in participating, please contact**: : [research assistant] at (780) XXX-XXXX or** **researchassistant@ualberta.ca**

Appendix R: Flyer

University of Victoria
School of Nursing

island health

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

Research Study: Living with serious illness

Are you living with Heart Failure and willing to share your experience of living with your illness?

You are invited to take part in a study that is being conducted through the University of Victoria and the University of Alberta.

We are seeking to gain an understanding of how people living with Heart Failure and their families make sense of the uncertainties in living with your illness.

Findings from the study will be used to help improve care and support for people and families living with Heart Failure.

The study will involve three interviews 60-90 minutes in length, at a time and location of your choice.

If you have a family who may be willing to share their experience, we would be interested in interviewing them as well.

If you are interested and wanting to learn more about the study please contact the Research Coordinators:

Marcy and Lacie at: **250-472-5371** email: **story@uvic.ca**.

Approval of this study can be verified by the Island Health Research Ethics Department at: 250-370-8620 or researchethics@vih

Appendix S: Participant Information Form

11405 87 Avenue
University of Alberta
Edmonton Alberta T6G 1C9
www.nursing.ualberta.ca

PARTICIPANT INFORMATION FORM

Title of Study: Living with Life-threatening Illness: Narratives of Liminality

Principal Investigator (Researcher): Anita Molzahn

University of Alberta Researchers: Alex Clark, Kara Schiff Makaroff

University of Victoria Researchers: Laurene Sheilds, Elizabeth Borycki, Anne Bruce

Why am I being asked to take part in this research study?

You are invited to join this study because you have unique experiences to share as you live with renal disease or heart failure. We are interested in what you experience as you live with a serious illness.

This is part of a larger study in Alberta and BC, with people who have renal disease, heart failure, chronic obstructive lung disease, or advanced cancer. There will be about 40 people living with illness in this study. There will also be about 40 family members in this study.

This study is not a part of standard treatment for these conditions.

Before you decide, someone working with this study will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

The purpose of this study is to hear peoples' stories of living with serious illness. We want to understand how these experiences affect their lives.

We will share what we learn from this study with other health care workers. We hope that by hearing and understanding these stories, they will get better at helping patients and families when they are living with serious illness.

What will I be asked to do?

If you volunteer to take part in this study, you will:

Give some information including your age, gender, education, and religious or spiritual affiliation.

Take part in 2 interviews:

They will be 60 - 90 minutes each. We will record these interviews. After the interview, the recording will be transcribed into written form.

The interviews will be somewhere that is convenient for you.

First interview:

You will be invited to share your experiences of living with illness and uncertainty.

At the end of 1st interview, you will be given a digital camera. We would like you to take pictures anything in your life that shows what it feels like for you to live with the uncertainties of life-threatening illness.

Please take as many photos as you wish, and choose 10 photos that you would like to discuss at the 2nd interview.

This camera will be shared with the family member who is also participating in this study.

A guide for taking these photos will be left with you.

Second interview[15]:

About 6 months after the 1st interview.

We will download the 10 images you have chosen onto a computer
(but not delete them from your camera)

We will look at the images with you, and ask you to tell how they show your experience of living with serious illness.

---

[15] This step is related to a major CIHR study.

Talk with someone on a telephone call[16]:

A month or two after the 2nd interview, we will call you for a 20-30 minute talk.

We will call you to ask any questions we might still have about your comments and thoughts from the 1st or 2nd interviews.

The digital camera which you will use between the 1st and 2nd interview will be left with you as a gift. If you are unable to take part in both interviews, or if you withdraw from the study for any reason, you may keep the digital camera.

What are the risks and discomforts?

Taking part in this study will take some of your time for the interview. We will make every effort to arrange times and places that are convenient for you.

Talking about your experiences with illness may bring up sad or upset feelings, or make you feel tired. If this happens, we will make sure we take time to help you, provide support, and if you need or want it, a referral to people who will be able to help you with any worries you have.

We do not expect you to experience any problems because of this study, but it is not possible to know all of the risks that may happen in a study. The researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

You might find that talking with someone who is interested and educated in this area to be helpful. But you may not get any benefit from being in this study.

Do I have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care that you are entitled to. If your family member choses to withdraw from the study at any time, you may still continue if you wish.

Every time we meet with you, we will go over this consent form again. This is to make sure that you still want to take part in this study.

You do not have to answer any questions that make you feel uncomfortable.

If you stop for any reason, you will be asked if you are willing to leave the interview data and photographs in the study. If the data has already been analyzed, we may not be able to remove that information. We will make every effort to respect your request.

Will my information be kept private?

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

Information that can identify you will be taken out of all written records. Recordings and written records will be kept in a locked metal cabinet in the researcher's office. Number codes will be used instead of your name. Only fictitious names will be used for reports, articles or presentations. Any person hired to work on the study will sign a legal agreement to keep everything private.

We may use some of the photos you gave us when we share the results of this study with others. We will be sure to talk with you about using these pictures. We cannot promise complete privacy as someone could recognize people, places, or other objects.

We will not share any of the conversations between you and our researchers with your family members. We will also not share any of the discussion with your family member with you.

After the study is done, we will continue to safely store your information from this study. At the University of Alberta, we keep data stored for at least 5 years after the end of the study. A copy of the 10 photographs you shared with us will be kept for 7 years. The written data from your interviews will be kept for research on improving the quality of life for people living with life-threatening illness.

How will the researchers share the information they learn?

We will create a set of videos that tells the stories and key messages from the study. They will be easy to find on the study website.

We will create a photography display using information from the interviews and some of the photographs. Academic articles will be re-written for lay audiences for magazines, newsletters and our project website.

Your name will not be used but your words or your photographs may be used.

What if I have questions?

If you have any questions about the research now or later, please contact one of:

Dr Anita Molzahn at	780-248-1401
Dr Alex Clark at	780-492-0752

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no connection with the study investigators.

This study is funded by the Canadian Institute of Health Research (CIHR). The researchers are getting money from CIHR to cover the costs of doing this study. You are free to ask for any details about this compensation from the Researcher.

Appendix T: Consent

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

University
of Victoria
School of Nursing

11405 87 Avenue
University of Alberta
Edmonton Alberta T6G 1C9
www.nursing.ualberta.ca

CONSENT

Title of Study: Living with Life-threatening Illness: Narratives of Liminality

Principal Investigators: Anita Molzahn Research Office: 780-248-1401

Alexander Clark Research Office: 780-492-0752

Study Coordinator: TBA Phone Number: 780-xxx-xxxx

	Yes	**No**
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Form?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are	☐	☐

participating in this research study? If so, give his/her name: __________________	
Who explained this study to you?	______________________
I agree to take part in this study:	
Signature of Research Participant:	______________________
Printed Name:	______________________
Date:	______________________
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.	
This should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)	
Signature of Investigator or Désignée:	______________________
Date:	

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM

AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix U: A semi-structured questionnaire

Interview Questions

Below are the sample questions that were provided in the ethics application:

Sample Questions for the Patient:

Tell me about living with HF.

How have you experienced uncertainty in living with serious illness and how has this uncertainty impacted your life?

How do you describe/talk about your serious illness? Who do you share your experience of serious illness with?

How have your experiences changed as your illness has become more serious?

Is there a time that stands out for you in coming to face living with HF? Please describe that time and its impact in your life.

In living with a serious illness, how have your thoughts on facing your own mortality changed (if at all)

What do you know now that you didn't know before you developed HF?

What is important to you now?

How has what you value in your life changed or been impacted by your experience of living with life-threatening illness?

We've talked about some of what is important to you and about your values; have these influence how you take care of your own health?

Can you tell me about times since your diagnosis when you were struggling with the big questions of life? What questions came up for you?

Can you please tell me about any aspects of living with HF that are challenging to speak about? (Note: this question has been used in past research and we have found it to be very beneficial. When asked to speak about challenging aspects of the illness experience, participants often tell us about experiences they believe others do not want to hear about OR that are difficult to fully describe (physical experiences). They sometimes will tell a researcher about an aspect of their experience that they're not comfortable telling family or healthcare professionals about. We are also using the photo aspect of the study to access experience that is difficult to articulate through words alone.)

Tell me about the care you have received from family members and healthcare providers as you have lived with HF.

What support (healthcare provider or care giver support) has made a difference for you in living with your illness?

What would you like health care providers to know about your experience of living with serious illness?

Appendix V: An Empirical Study: Detailed Methodology

Due to word length limitations, it was not possible to include a detailed and comprehensive overview of the method employed in the manuscript of the concept analysis study developed for publication and included in Chapter 4, above. Accordingly, this appendix provides such an overview for the study, whose purposes, as noted above, were:

- What kinds of values have effects on self-care decision-making in patients with HF?
- How do patients' values impact HF self-care decision-making?

Research design. *Research methodology* refers to "the general approach the researcher takes in carrying out the research project" (Leedey & Ormond, 2005, p. 14). Given that the main focus of this study was to understand how patients' values impact self-care decision-making in HF patients, a *qualitative methodology* was applied. Strauss and Corbin (1990) state that a qualitative approach yields results that cannot be gathered using quantitative methods, and generally refers to research that leads to understanding people's lives, stories, behaviors, organizational functioning, social movements, or interactional relationships.

A qualitative research methodology allowed me to comprehend the reality of individuals' behaviors, beliefs, and thoughts (Pulpit & Martin, 2010; Thorne, 2000), and to provide the answers to the questions of this study, all of which start with "how" (Given, 2008). This was preferable to experimental approaches, which are based on structured questions and concerned with statistical analysis; given the difference in the kinds of data examined, such experimental approaches are not always appropriate for studying questions that seek to understand the meaning of everyday life (Pole, 1999; Coughlan, Cronin, & Ryan, 2007).

Focused analysis. This was a focused study that analyzed data concurrently with a larger study, entitled "Living with Life-threatening Illness: Narratives of Liminality". The larger study -

for which the data were generated to understand the experiences of patients living with advanced disease and their families – This study was led by principal investigator *Dr. Laurene Sheilds*. The co-investigators of this study were *Drs. Anne Bruce, Elizabeth Borycki, who are faculty members at the University of Victoria and Drs. Anita Molzahn, Alex Clark, and Kara Schick Makaroff are faculty members at the University of Alberta*. The larger study recruited 40 people living with illness and 40 family members in this study.

I was involved in this larger study, in developing questions that directly sought to understand patients' values. They included:

What is important to you now?

How has what you value in your life changed or been impacted by your experience of living with life-threatening illness?

We've talked about some of what is important to you and about your values; have these influenced how you take care of your own health?

I was closely involved in providing definitions for the concepts of *self-care* and *patients' values* for the study and discussed the two elements with a research assistant prior to conducting interviews with HF patients. From January to December of 2016, I also participated in the two-hour team meetings that were conducted regularly via Skype every other week at the University of Victoria focusing on the research process as well as the analysis of transcripts related to other life-threatening illnesses (e.g. renal disease). My involvement in analysis of the transcripts was related to considering the function of patients' values – the specific concern of the current, focused analysis, upon which I commenced work during 2016. I analyzed the data for this focused study after the completion of an ethics review by the Health Research Ethics Board (HREB). Analysis was concurrent with data collection and continued after data collection.

Interpretative phenomenological analysis. This study applied interpretative phenomenological analysis (IPA) consistent with its phenomenological origins, aims to understand participants' sense of their personal and social world, and "the meanings particular experiences, events, states hold for participants" (Smith & Osborn, 2007, p. 53). In IPA, the researcher plays an active role in the research, which was a "dynamic process" (Smith & Osborn, 2008). Indeed, researchers attempt to get close to the participants' personal world, and try to understand and make sense of participants' views from their own perspectives through a process of interpretative activity (Smith & Osborn, 2008).

Thus, the process of interpretation was intellectually linked to hermeneutics. The term *hermeneutics* originates from "Hermes, the Greek messenger god who helped humans understands what the gods were trying to say" (Ratner, 2002, p.9). Moreover, in Smith and Osborn's words (2008), IPA is a "*double hermeneutic*" (p.53), which combines an empathic hermeneutics and a questioning hermeneutics.

Accordingly, I analyzed data using IPA for this study by first seeking to understand HF patients' views of "what it [the experience of self-care] is like" (empathic hermeneutics). Then, I began to ask critical questions of the texts, such as the following: *What is the person trying to say about his or her values? Are patients' values explicit? Do I have a sense of the values of which HF patients are not aware and which are embedded in the decision-making process*? I subsequently used a second and related set of critical questions to try to understand how values influenc self-care decision-making. The following critical questions were asked: *How does the value work? Does the value impede or facilitate self-care behavior? Does the value always* *function the same way? How does the value work in relation to other values? Are there other individual or contextual factors to influence self-care decision-making (and how)?*

These techniques allowed me to interpret the data in ways that had not been considered in other methods. IPA was suitable for this research, by virtue of the following considerations. First, the central analytic concerns of such methods are related to the individual's psychological world which was consistent with the purpose of this study (values). Second, IPA is a scientific method that offers a diligent and systematic process of data interpretation. Third, it was rooted in critical realism (Bhaskar, 1978), which was in line with the theoretical foundation of this study. From a critical realist perspective, IPA accepts that reality exists independently of human conceptualisations, and different meanings from different individuals' experiences – those of participants as well as researchers– are different parts of that reality (Fade, 2004). Accordingly, this method was suitable because individuals' values are not always implicit and need to be interpreted based on the point of view of the participants and on knowledge we have gained from the first two studies. Hence, this was analyzed by trying to make sense of participants' statements about how their values impact self-care decision-making.

Sampling. The participants were recruited from a convenience sample of 12 HF patients who were: over 6o years of age, diagnosed with HF (Class II or II as New York Heart Association), being treated in a heart function clinic, having experience of progression of disease or exacerbations during the previous year, aware of their illness, and interested in participating in the study. Patients were excluded if they were Non-English speaking, suffering from an acute exacerbation, or experiencing cognitive impairment, given that such condition conditions were likely to interfere with providing valid data, as well as obtaining consent. This number adhered to the guidelines for samples in phenomenological studies proposed by Creswell (1998), who suggested sample sizes of five to 25, and Morse (1994), who placed emphasis on at least six participants. Generally, fifteen is the smallest acceptable sample size in qualitative research (Bertaux, 1981; Guest, Bunce, Johnson, 2006). For IPA studies, however, there is no specific rule for the sample size; it depends on the level of analysis and reporting and the richness of the individual cases (Smith & Osborn, 2008). IPA has been conducted with samples of one, four, nine, 15 and more. As such, the 12 transcripts were suitable, since all contain rich data about the patients' values, which we anticipated was implied frequently in the context of responses.

Data collection. HF patients who met the inclusion criteria were recruited by three research assistants via convenience sampling over nine months between January 2015 and December 2015 from two urban sites in Western Canada: The Heart Function Clinic, located in Edmonton, Alberta and Island Health Authority, located in Victoria, British Colombia. Both centres provide a broad range of services to HF patients. Patients who were willing to participate in this study received a flyer (Appendix Q) describing the study and additional information about the study. Personal information including contact information, demographic information, history of experiencing HF, and history of comorbidity was collected. A brief explanation of the study and its process was provided to potential participants, and a preferred interview time was discussed. A set of in-depth interviews were conducted for approximately 90 to 120 minutes by a team of experienced interviewers based on a guideline (Appendix P). This method was appropriate, as the personal and in-depth quality of the interviews allowed patients to reveal their underlying beliefs (King & Horrocks, 2010; Schostak, 2006). The interviews were conducted at a time and place that was convenient for participants. Informed consent (Appendix T) was explained and obtained at the time of the interview. The in-depth interviews of participants were digitally voice recorded. Participants were interviewed using a semi-structured questionnaire

(Appendix U), which was developed and refined based on previous literature and in consultation with the research team. In addition, information about age, gender, ethnicity/heritage/cultural affiliation, work status, education level, self-described socio-economic status (e.g. living in poverty, working class, middle class, upper middle class), and living arrangements (alone, living with others) was collected during the interview.

Ethical considerations. Ethics approval for this study was obtained from the host Research Ethics Board, and was adhered to throughout the process. Interviews were conducted after the informed consent was agreed to and signed, and took place in a location determined by the participants. The transcripts, audios, and field notes were kept and used anonymously in a secure virtual research system. The interviews were paused upon the participants' request until they were ready and able to continue. Participants were informed that they could withdraw from the study at any time. Resources and supports were also made available in case the participants experienced any discomfort during the interviews. Field notes were recorded immediately after interviews. All interviews and field notes were transcribed by experienced transcriptionists. Transcripts were cleaned by the interviewer who conducted the interviews in order to ensure the quality of data.

Data sources. This first phase of the study collected a total of 12 transcripts of semi-structured in-depth interviews that were conducted with HF patients as part of the larger study, together with audiotapes and field notes. The first interviews aimed to understand HF patients' experiences using the semi-structured interview. These data sources provided information regarding what was experienced, what was learned through interaction with participants, and what was observed during the interview (Kawulich, 2005). The audiotapes also helped to reduce the likelihood of losing information through transcription. This was important given that critical emotional content (Poland, 1995) or silent data, such as laughter, silences volume, pitch, pace, and tone, are difficult to convey through transcription (Poland, 1995).

Analysis. The assumption in IPA is that analysis was undertaken to learn about the participants' psychological world in particular, those "in the form of beliefs" (Smith & Osborne, 2008, p.66). This premise was consistent with the main focus of this study, which views values as a key aspect of the psychological world of HF patients. Understanding the complex meanings of respondents' statements was central in this method. To do so, a sustained engagement with the text was required to be able to capture these meanings to identify respondents' values, and to go deeper to learn about their mental and social world. In order to analyze the data in IPA, the following step-by-step approach was adopted.

Looking for themes in the first transcript. The transcript was read and re-read several times, so that the researcher was as familiar as possible with it. The process of analysis was continued by annotating what was essential, thought-provoking, and relevant to patients' values in the participants' quotes. The reason for undertaking multiple readings was because in each reading the likelihood of producing new insights were increased (Smith & Osborne, 2008). It was anticipated that, in reading the transcript, some parts of the text were richer than other parts and required comments and interpretation. (Smith & Osborne, 2008, p. 67) Some of the comments may involve summarizing, paraphrasing, offering preliminary interpretations, and noting similarities and differences, echoes, amplifications and contradictions (Smith & Osborne, 2008).

This process was continued for the whole of the first transcript. Then researcher returned to the transcript to identify themes; these were documented on the right side of the transcript. The initial notes were reduced to concise phrases. These themes involved a higher level of abstraction and may require more terminology that was based both on the list of values from the theory of human values (Appenix J) and on other values that might be developed through the systematic review of literature on patients with HF. At the same time, the transcripts of participants' statements were re-read to ensure that the themes were relevant, that further themes could evolve, and that the data supported the provisional themes, thus supporting the validity of my approach.

Hence, at this stage, the high level of expressions was found to allow theoretical connections within and across cases. This transformation of primary comments into themes were sustained through the whole transcript. At this stage, the entire transcript was also kept and selection of particular passages was not done. The richness of the data was determined by the number of the emerging themes. Hence, in order to transfer comments to themes based on the knowledge of concept analysis of the values, hand coding was more suitable than Computer Assisted/Aided Qualitative Data Analysis (CAQDAS).

Hand coding process. Although CAQDAS is known for facilitating and simplifying the coding process (Brown, 2002, Davis & Meyer, 2009) and for allowing visualizion of data in the analytical process (Garcia-Horta & Guerra-Ramos, 2009), there are concerns that highlight the merits and importance of hand coding in this study. These include the possibility of mislabelling and potentially losing important information (Devis & Meyer, 2009), experiencing a computer malfunction (Sparkes &Smith, 2013; Devis & Meyer, 2009), or providing too many codes (Sparkes &Smith, 2013; Klenke, 2008). Each of these problems could affect the interpretation of the data from the social context as misconception (Fielding & Lee, 1998; Sparkes & Smith, 2013; Thompson, 2002; Weston et al, 2001), and thus the trustworthiness of research. Maintaining contextual distance between the researchers and the data prevented mutual association between the coding process and the process of understanding a phenomenon (Weston et al, 2001) that may obscure the intended meaning of a participant's response (Devis & Meyer, 2009; Lee, & Fielding, 2004; MacMillan & Koenig, 2004; Mangabeira; Weitzman, 2000). Given the weaknesses that have been cited for using CAQDAS, particularly in terms of providing textual-level work rather than conceptual level work (Richards & Richards, 1994), this study used a hand coding process. Hence, the text was marked with a pen, notes were written, and results were gathered manually.

Connecting the themes. In order to make sense of the links between themes, this stage included a more analytical or theoretical comparison. The emergent themes in a given transcript was listed on a sheet of paper to discover the connections between them. The themes were clustered based on the sense of connectedness between them, which encapsulated aspects of the functions of patients' values in self-care decisions. The clustering process was constantly checked by re-reading a transcript to make sure that the relationship between themes was accurate. The participant's quotes were provided in order to justify related themes.

Next, a table of the consistently ordered themes was made to clearly represent the participant's most important concerns about a specific subject. Each cluster was identified according to a superordinate theme and was given an identifier to facilitate finding the original source of the emerged theme. The identifier included key words (the first words of the section of the transcript related to the theme) and a page number within the transcript. During this process, some of the themes may be omitted if they are neither appropriate in the emerging structure nor are strongly supported within the transcript (Smith & Osborne, 2008).

Continuing the analysis with other transcripts. This analysis was continued for the transcripts. The researcher searched for and connected themes, creating a table based on the orientation of themes within the table from the first transcript. Awareness of the themes from the first transcript made it possible to identify shared, different, and new themes in the subsequent transcripts and simultaneously provided more evidence for the extant themes. Once each transcript has been analyzed through the interpretative process, a final table of superordinate themes was made. To do so, themes were prioritized based on their_prevalence within the data, as well as the richness of the specific text that highlights the themes; this reduced some themes that are weakly supported.

Writing up. The writing phase involved the transition from the final themes to the write-up of a narrative format. This narrative argument consisted of supporting verbatim quotations from the transcripts. In doing so, HF patients' responses were distinguished from our interpretations. The results contained the emergent thematic analysis which were followed by the link to the extant literature in the discussion section.

Verification. This study used several verification strategies to rectify both the direction of the analysis and the development of the study (Morse et al., 2002) as follows:

Methodological coherence. The coherence was achieved, particularly by ensuring interdependence between research questions and analytic procedures (Morse et al., 2002). The IPA was the most suitable method for two main reasons: (a) this method seeks to understand individuals' psychological world which was consistent with the main focus of this study. In other words, values are types of HF patients' psychological worlds (Smith & Osborne, 2008) that are needed to be understood through processes of interpretation, and (b) the element of rigor was inherent in the IPA, given that a self-correcting strategy (Morse et al., 2002) overarches almost the entire process.

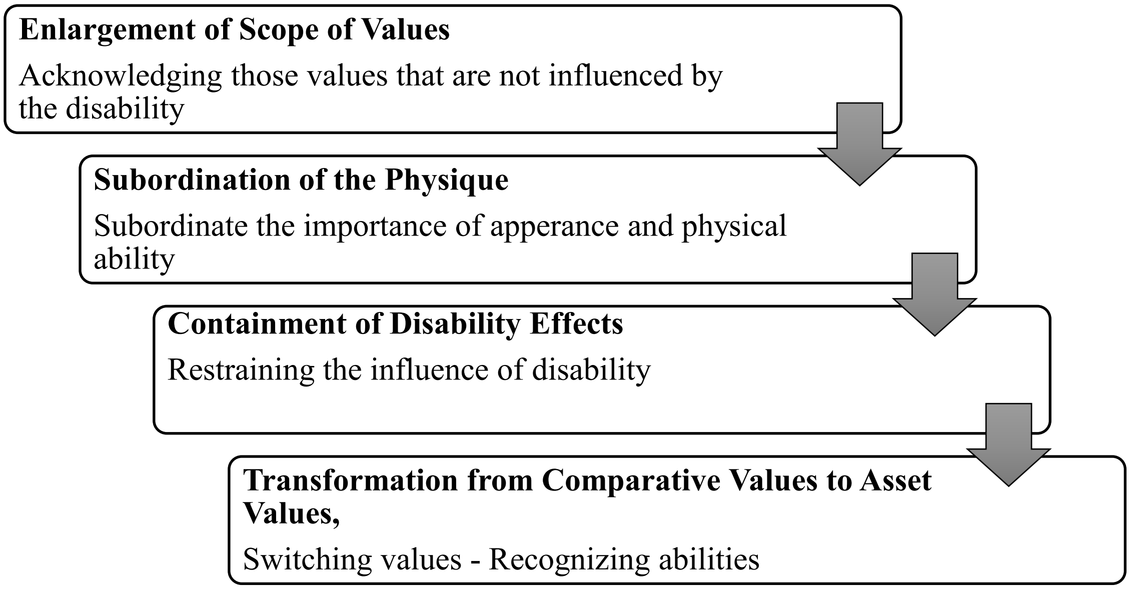
Self-correcting. The IPA, as an iterative method, requires researchers to move back and forth frequently between comments, themes, and clusters, as well as to read transcripts– to ensure congruence between this process and each respondent's expression (Smith & Osborne, 2008). This significant process increases the level of self-correcting and responsiveness of the investigators by listening to the data rather than adhering to a protocol (Morse et al., 2002), which can be a serious hidden threat to the validity of the study (Morse et al., 2002).

Rigor in interpreting (Ratner, 2002). It has been noted that the researcher's subjectivity may influence the possibility of objectively understanding psychological phenomena. As such, to comprehend peoples' psychological worlds (e.g. values), our subjectivity must be organized appropriately by well-defining the concepts so they can be identified explicitly (Ratner, 2002). To do so, data in this study were treated based on the two fundamental studies: the concept analysis study, which refined the concept of *values*, and the SR study, which provided some insights in relation to the functions of patients' values in self-care decision making. This allowed me to establish the degree of accuracy/objectivity to ensure that the results were based on the rules (Gergon, 2001) with a strong theoretical and conceptual foundation (Ratner, 2002), and optimal validity achieved (Morse et al., 2002).

Triangulation. *Triangulation* minimizes bias and establishes the validity of findings (Murphy et al., 1998). This study used two triangulation methods, (a) *theory triangulation,* which involves the use of multiple perspectives, by involving of researchers with different status positions as a professor and PhD student, who are expected to employment of specific theoretical approaches. Therefore, the discussion on all steps including the interpretation of data established the validity of data. The second method (b) *Investigator triangulation* refers to the involvement of different researchers in the same study and was used through consulting with the research principal, Dr. Alex Clark and the assistant researcher(s) (who collected the data).

Audit trail. In order to ensure the rigor of the analysis, by using an audit trail, all analysis sessions, outcomes, analytic theoretical insight, assumptions, personal responses, and challenges were immediately and comprehensively generated (Rodgers, 2007). Hence, all methodological decisions (Rodgers, 2007) and phases of analysis were clearly and consistently recorded. As such, all phases relevant to the emerging notes/comments, transforming primary comments into themes, and connecting, clustering, and prioritizing the themes were prepared and saved into a Word document on the computer (Rodgers, 2007). In addition, the researcher reflexivity persuade by writing my background, my philosophical approach, and my emotional responses to the data, the analysis procedures, and the final outcomes (Rodgers, 2007).

Appendix W: Wright's theory: Transformation of values during disability



Appendix X: Methodological Appropriateness: The CMNS Approach

CMNS was applied to synthesize qualitative, quantitative, and mixed-methods data. This was grounded upon the fact that using these types of data can generate more cohesive and comprehensive data (Creswell &Plano Clark, 2011, 2007; Tashakkori & Teddlie, 2010, p.432). This is because the blind spots inherent in individual methods are avoided and *complementary*" (Maxwell 2010) data are brought together. Quantitative studies and qualitative studies together provide knowledge, which led me to a deeper understanding of patients' values and how they, along with other individual and contextual factors, impact HF self-care decision-making.

"[A mixed-methods] study consists of a qualitative or quantitative core component and a supplementary component (which consists of qualitative or quantitative….)" (Morse (2009), p. 20). The core component of this method is qualitative data. This is so for two reasons: 1) qualitative data provide the theoretical foundation for quantitative data (Morse, 2009, p. 115), 2) and they provide unique contributions to understanding the complexity of self-care in HF (Clark et al., 2009; Siabani, Leeder, & Davidson, 2013; Thomas, 2011) and identifying beliefs that underlie self-care behaviors in HF patients (Clark et al., 2009; Cottrell, Denaro, & Emmerton, 2013; Kadal et al., 2009; van der Wal, 2010). Quantitative studies, by contrast, were considered as supplemental components that enabled me to address aspects of complexity and conveyed the complementary information.

Application of Meta-ethnography for Synthesizing Theoretical Knowledge

Meta-ethnography is the rigorous approach, that was used to synthesise study findings. It provided systematic methods for translating qualitative studies into one another. These methods facilitate uncovering and analyzing any kind of relations (including reciprocal, refutational, and/or lines of argument) between the results of the studies. Given that such an approach is based on the translation of interpretations (*grounded explanations*) into one another rather than the compilation of the similarities and dissimilarities between studies, the results are expected to be generalizable. Meta-ethnography allows researchers to synthesize not only ethnographic studies but also other qualitative, interpretive studies (Noblit &Hare, 1988).

Table X.1

The Applicability of Meta-Ethnography

1. Meta-ethnography is based on translations of interpretations of the research into one another to construct adequate explanations and understandings (Noblit & Hare, 1998).
2. “Interpretations come in the form of narratives and as a form of communicated knowledge” (p.33).
3. Meta-ethnography aims to “synthesize ethnographies or other qualitative, interpretive…or multiple studies” to construct an interpretive explanation (p.9).
4. Meta-ethnography is based on the notion that “all explanation is essentially comparative and takes the form of translation” (p.25).
5. The exclusion of studies in synthesis attempts should not be based on methodological differences (cited in Noblit & Hare, 1998).
6. Converting quantitative data into qualitized data and narratives is possible through five types of narrative profiles (Tashakkori & teddlie, 1998).
7. Interpreting quantitative data can be optimized by making efforts to answer the critical questions.

Given that meta-ethnography is typically applied to qualitative studies, the application of such a method to the analysis of quantitative data raises the important question of whether this method is applicable. This crucial concern can be explored by drawing on the following perspectives (for a full rationale, see Table X.1).

Commonalities between quantitative and qualitative data. The reluctance to apply meta-ethnography to quantitative data stems from a strict polarization between qualitative and quantitative studies. The categorization of research into quantitative and qualitative types facilitates our understanding about the differences between such methodologies. However, this division could be problematic if it is viewed as absolute. Indeed, strict polarization is a “false distinction” (Voils, Sandelowski, Barroso, & Hasselblad, 2008) that hinders our understanding of the commonalities of those methods and restricts me from merging qualitative and quantitative data. For example, patterns and relationships that are part of the interpretable data regarding a particular phenomenon might emerge from quantitative studies but be overlooked in qualitative research. Just as important, both qualitative and quantitative research can contain aspects of the other (Harden, 2010). Noblit and Hare quote the assertion of Hunter et al. (1982) that meta-analysis should be an interpretive endeavour of studies based on topical similarities rather than methodological ones. The division between qualitative and quantitative methodologies is based on untested theory when, in fact, the value of a study is based on its contribution to a synthesis rather than on its methodological affinity. Meta-ethnography, thus, has the potential to deal with quantitative as well as qualitative data (Pope et al., 2007).

Critical interpretive synthesis (CIS) is an approach that is grounded in the meta-ethnography method and is applied to synthesizing qualitative and quantitative studies (Dixon-Woods et al., 2006). The CMNS is a modified form of the CIS approach. The MNS approach seeks to synthesize qualitative, quantitative, and mixed-method studies. By relying on narratives, which are extracted by answering critical questions.

Narrative construction of meaning making. Narrative, which is also called *minimal story,* constitutes meaningful relations between events that might be metaphorical, metonymical, or thematic. For instance, “beliefs are important” is not narrative since it does not convey meaningful information. However, the text “religious beliefs are important because they influence making non-adherence decisions" is a narrative because of the presence of a derivable meaningful relationship between actions (Herman & Vervaeck, 2005).

Although, meta-ethnography has traditionally to put emphasis only on narratives drown from qualitative research, the CMNS approach, like the CIS approach, uses both qualitative and quantitative studies, and the focus is on discovering what is beyond (meta) the narratives. However, in contrast to the CIS approach, in which key concepts are extracted from the *findings of qualitative studies* and *discussion section of quantitative studies*, the CMNS approach uses all kinds of data, including findings and discussions sections from both qualitative and quantitative studies.

Identifying qualitative aspects of quantitative data. Quantitative data have qualitative aspects that can be extracted through the process of transforming quantitative data into narrative data (Tashakkori & Teddlie, 1998). Tashkori and Teddlie developed five types of narrative profiles: an average profile, a comparative profile, a holistic profile, a modal profile, and a normative profile. These profiles generate narratives from various types of quantitative data, such as means, comparison results, frequently occurring attributes, and holistic data. These profiles enable a researcher capture important data that have the potential to be qualitized and converted into the narratives. Hence, through the five systematic profiles, all data that have the potential to be converted into narratives are transformed.

Qualitizing data. As mentioned earlier, the qualitizing technique, which converts quantitative data into qualitative data, enables the researcher to conduct a meta-ethnography as a means of synthesising qualitative research. In doing so, five types of profiles can be applied concurrently, as follows:

1) *Modal profiles (narratives were constructed from data on the most frequently occurring characteristics of participants),*
2) *Average profiles (narratives were constructed from data relating to the mean of the particular variables),*
3) *Comparative profiles (narrative were constructed from data on comparison of key outcomes),*
4) *Holistic profiles (narratives were constructed based on a combination of the modal, average, and comparative profiles), and*
5) *Normative profiles (narrative were constructed based on comparison of results with a standard).*

As such, these five profiles enable us construct narratives. Those five narratives are usually linear and may not be in-depth, but they are participants' answers to the constructed questions that reveal participants' perspectives that might be overlooked in qualitative studies. Missing these data may undermine the trustworthiness of the results, in particular because having more data derived from a number of participants' responses which increases the confidence and trustworthiness of the relevant themes. Furthermore, since there are instances in which quantitative studies might pose some open-ended questions, quantitative research can also elicit participants' narratives. While some of the constructed narratives were interpretive in nature – in particular, the ones made through the holistic profile – further efforts are made to optimize the extent of the interpretation of quantitative data. In this study such data were identified by frequently reading and reflecting on the whole findings and identifying answers to the following critical questions: What is this study trying to say about patients' values? Are patients' values explicitly identified? If so, what are they? How do participants' answers to the questions enable me to gain a sense about patients' values and their influence on self-care decision-making? Do patients' values facilitate, hinder, or nullify self-care adherence? Are there other individual or contextual factors (such as age, gender, severity of HF) that influence patients' values and self-care decision-making? And how? How different (or similar) are patients, family care givers, and health professionals' perspectives about the influence of patients' values in self-care decision-making? This approach allowed us to enhance the interpretation of quantitative data. It provides a greater understanding of phenomena in greater depth (Johnson & Christensen, 2012) and consequently facilitates the investigation of relationships between components from two types of data.

As such, in contrast to the CIS, the CMNS approach provides a step-by-step approach to generate narratives from quantitative data by applying the five systematic profiles as well as critically questioning the data.

Hence, through the process of reading and re-reading the studies attempts were made to identify all interpretive metaphors, themes, concepts, and quotes that were explicitly or implicitly related to these values. For example, data related to HF patients' values may be buried in an article that focuses on HF patients' beliefs. The key metaphors, phrases, ideas, and/or concepts (and their relations), then were compared with each other and determined whether the relationship between studies is reciprocal translational analysis (RTA) (studies are about similar things), refutational synthesis, (studies refute each other), and/or involves and lines-of-argument synthesis (LOA), (studies suggest a line-of-argument) about patients' values and the impact of values on self-care decision-making in HF patients.

As such, in contrast to the CIS approach, which focuses mainly on lines-of-argument synthesis, the CMNS approach applies all three strategies of the meta-ethnography to translate the findings from each individual study into those of the others. This was based on the assumption that in a systematic review, particularly in a mixed-methods study, that the number of included studies is expected to be high, coming up with the analogous, refutational, and which lines-of-argument synthesis is promising. Subsequently, the line of argument, reciprocal and reputational translation synthesis implied for the pool of qualitative and qualitized data in order to synthesis the inferences and higher order of abstraction by translating the interpretations or grounded explanations of one study into the interpretations of another (Noblit & Hare, 1998).

Appendix Y: Summary of the Results

Values are defined as core beliefs, which are abstract and subjective in nature and perceived as very significant to individuals. Values conceptually are differentiated from attitudes and beliefs as follows: attitudes are evaluative associations and directed toward an object (people, behaviors, events, places) and the situation in which the object is established (e.g. positive opinion of a patient with HF about eating out with friends at a restaurant on Christmas Day). Beliefs are the convictions that a statement is true (e.g. self-care improves HF patients' wellbeing; I can adjust my Lasix dose based on my daily weight).

Values are integral in patients' self-care decisions and can be categorized into two groups; emotional values and functional values. Each group is categorized into three groups; self-related, other related, and health professional-related values. Self-related values are tied directly to intimate personal feelings or related to individuals' life circumstances. Other-related values, which are fundamentally socially-based, are related to benefits received from society and social obligations. Health professional -related values, which are expectation-based, are associated with care benefits received from health-care professionals and interactions with them. Each type of values can be involved in both adherent and non-adherent decisions.