Heart Failure Self-Care: An Evolutionary Concept Analysis

By

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Bachelor of Science in Nursing, University of Ottawa, 2014

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We acknowledge with respect the Lukwungen peoples on whose traditional territory the university stands and the Songhees, Esquimalt, and WSANEC peoples whose historical relationships with the land continue to this day.

Supervisory Committee

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Abstract

Self-care is a central concept in heart failure management and a large focus of nursing practice. Yet, the uptake of heart failure self-care has been somewhat uncritical and detached from the broader social, political, economic, and ideological context in which it is located. Therefore, heart failure self-care was explored using Rodger's evolutionary concept analysis approach to identify antecedents, attributes, and consequences with attention to context, time, application, and meaning. Four categories of antecedents were identified during the analysis, which included: 1) person; 2) partner; 3) provider; and 4) system. Five attributes were revealed, which comprised of a set of behaviours that are universally applied and measurable; an active and demanding daily process; an experience that ranges from autonomous to assisted care; a standard that requires compliance and monitoring; and a strategy to cut healthcare costs and utilization. Consequences included objective (i.e., observer reported) and subjective (i.e., patient reported) outcomes. This concept analysis suggests that heart failure self-care (as a concept) tends to focus on individual behaviours to the detriment of social and structural determinants of health. It also shifts responsibility for the care and outcomes away from the health care system and onto the individual. Furthermore, self-care interventions have historically been used to manage costly chronic conditions and ultimately, to limit healthcare expenditures. This thesis can pave the way forward for a more robust conceptualization of heart failure self-care or possibly, to push for the development of a new concept that reflects the current state of knowledge and focuses beyond the *self*. In light of these findings, recommendations are made for nursing theory, research, and practice.

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Acknowledgements

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CHAPTER 1

RESEARCH PROBLEM

This chapter provides an overview of the research problem and states the objectives for this study. It also offers a brief description of the research paradigm in which this study is located.

1.1 Background

Heart failure (henceforth HF) was originally defined in 1858 as "chronic myocarditis" by Rudolf Virchow in *Die Cellularpathologie* (Ziaeian & Fonarow, 2016). The definition of HF has evolved considerably over time. It is now understood to be a complex chronic condition with multiple underlying causes and risk factors that lead to inefficient heart pumping and decreased cardiac output (Ezekowitz et al., 2017). HF is a syndrome and not a disease. Its diagnosis relies mainly on a careful history and physical examination, along with objective evidence of cardiac dysfunction and reduced cardiac output (Ezekowitz et al., 2017). Individuals diagnosed with HF with reduced ejection fraction (HFrEF), also commonly known as systolic HF, have an ejection fraction of 40% or less, meaning they have an enlarged left ventricle that has difficulty pumping sufficient blood to the body. Those diagnosed with HF with preserved ejection fraction (HFpEF), also known as diastolic HF, have a normal ejection fraction meaning that their heart pumps a sufficient percentage of blood to the body. Yet, their heart muscle is stiff and thickened, making it difficult for the heart to fill with blood. While HF may differ between individuals, clinical symptoms often present similarly; they can include dyspnea, fatigue, exercise intolerance, and pulmonary or systemic congestion (Ezekowitz et al., 2017).

HF is a major public health concern, with a prevalence of over 64.3 million adults worldwide (James et al., 2018). The Public Health Agency of Canada (PHAC) (2018) suggests that HF incidence appears to be declining, from 8.1 new cases per 1,000 in 2001 to 5.3 per 1,000

in 2013. However, during this same period, the number of Canadians living with HF grew by over 200,000 (PHAC, 2018). In 2018, over 700,000 Canadians lived with this complex chronic condition (PHAC, 2018). As Roger (2013) explains, progress in primary prevention has led to a decrease in incidence, while improvement in HF management has resulted in better survival and thus increased the prevalence of people living with HF. As the Canadian population ages and survival rates from cardiovascular disease continue to improve, the prevalence of HF will continue increasing over time, along with the need for HF care (Blair et al., 2013).

Multiple risk factors are associated with HF. Coronary heart disease carries the highest relative risk among conventional risk factors, with 20-25% of adults 65 years of age and older developing HF within five years of their first myocardial infarction (Blair et al., 2013). Other risk factors for developing heart failure include sex, age, race, cigarette smoking, hypertension, cardiac arrhythmias, valvular disease, low physical activity, obesity, and diabetes (Blair et al., 2013). Although less common than traditional cardiovascular risk factors, excess alcohol consumption, substance use, pregnancy, genetics, and viral infections can also lead to the development of HF (Ezekowitz et al., 2017). It is also important to note that the social determinants of health such as income and social status, employment and working conditions, and access to health care services contribute to HF incidence. In fact, a recent systematic review by Potter and colleagues (2019) showed a consistent relationship between low socioeconomic status and an increased risk of developing HF, independent of traditional risk factors.

Given the rising prevalence of HF, significant emphasis has been placed on early recognition, treatment, and management within community settings. The Canadian Cardiovascular Society treatment guidelines (2017) recommend HF therapy to improve survival and reduce morbidity, hospitalizations and symptoms while improving functional capacity and

quality of life. HF therapy includes pharmacological therapy, device or surgical treatment options, and non-pharmacological management (Ezekowitz et al., 2017):

- *Pharmacological therapies* have been shown to change the natural progression of HF. Contemporary pharmacological treatment for HFrEF typically involves three medications, often called triple therapy, although other medications may also be added depending on the circumstances. HF medications include angiotensin converting enzyme inhibitors, angiotensin II receptor blockade or angiotensin receptor- neprilysin inhibitors, beta-blockers, and mineralocorticoid receptor antagonists. These medications work on various pathways of the neurohormonal system and improve survival in patients with HFrEF.
- *Device treatment and surgical options* have steadily risen over the past decade. Cardiac resynchronization therapy (CRT) is a pacemaker that coordinates left and right ventricular function. Implantable cardiac defibrillators continuously monitor and regulate life-threatening arrhythmias. Both devices have been shown to decrease mortality and CRT pacemakers improve quality of life (Botto & Russo, 2012). Other advanced HF therapies include, for example, a left ventricular assist device. This mechanical pump assists the heart and is frequently used as a bridge while waiting for heart transplantation. Left ventricular assist devices are also an option as "destination therapy" in patients who are not eligible for heart transplantation. Heart transplantation can be considered for end-stage heart failure when no other treatment options are available, and no significant comorbidities are present.
- *Non-pharmacological management* typically includes lifestyle changes such as dietary changes, smoking cessation, reduction or cessation of alcohol and drug use,

immunization against influenza and pneumococcal pathogens, regular exercise, and daily weight monitoring. These activities seek to maintain or improve health, as well as to delay disease progression and prevent complications and hospitalization.

Unsurprisingly, challenges exist in managing HF at both the healthcare provider and patient level. At the provider level, family physicians have traditionally managed HF, although it has been acknowledged that family physicians often lack the skills, time, and support required for optimal management (Hayes et al., 2015). From the patient perspective, adherence to complex pharmacological regimens combined with follow-up requirements, blood work monitoring, and lifestyle changes makes HF self-care particularly demanding and challenging. As such, high percentages of people living with cardiovascular diseases struggle with treatment adherence (up to 50%), following exercise recommendations (61%), and lifestyle modifications, especially dietary changes such as sodium and fluid restrictions (66%) (Conraads et al., 2012; Frediani et al., 2013; Gallagher et al. 2017; Oosterom-Calo et al., 2013). Given these challenges, there has been an increasing focus on informal caregivers and their role in supporting HF self-care (Harkness et al., 2015). A growing number of studies suggest that outcomes are better when HF self-care is collaboratively performed with caregiver support (Lyons & Lee, 2018). Nevertheless, even with caregiver support, HF management remains demanding and time-consuming.

Challenges associated with the management of HF contribute to the rise in hospitalizations and associated costs. In fact, HF is one of the top five leading causes of hospital admission in Canada (Canadian Institute for Health Information, 2019). For example, a cohort study estimated that people who struggle with treatment adherence accounted for 22% of all HF-related hospital admissions (Lee et al., 2015). Furthermore, patients often find themselves

admitted to the hospital to manage acute decompensations, typically when they experience a sudden increase in pulmonary or systemic congestion. It is estimated that 1 in 5 patients admitted with HF will return to the hospital within 30 days (Heart & Stroke Foundation, 2016). This is due to worsening HF symptoms requiring diuretic and medication adjustments or another related cause such as pneumonia or renal dysfunction (Madelaire et al., 2019). Frequently, HF exacerbations and related issues are challenging to manage alone and require intensive support from healthcare teams to regain homeostasis. Frequent HF hospitalizations are expensive, costing Canadians $482 million per year and projected to cost $722 million per year by 2030 (Tran et al., 2016).

Over the past two decades, specialized HF clinics have been developed across Canada to reduce costs associated with frequent hospitalizations, improve the efficiency of HF management, and optimize patient outcomes. Recognizing the challenges faced by people living with HF, these clinics are run by specialized interprofessional healthcare teams that implement HF management programs designed to delay disease progression, encourage health promotion, and support self-care (Sargious, 2007). The Canadian Cardiovascular Society began recommending HF disease management programs in 2006, noting that such programs can educate patients to enhance self-care activities, apply evidence-based medical therapies, and provide follow-up monitoring by specially trained staff (Ross et al., 2006).

HF clinic teams are typically interprofessional. They include heart failure nurse specialists and cardiologists or internal medicine specialists. They may also include pharmacists, dieticians, and nurse practitioners. HF nurse specialists, in particular, are responsible for supporting self-care activities to promote and optimize health and delay disease progression. They provide educational interventions to equip people living with HF with the necessary

information and skills to manage their health, make lifestyle changes, improve their quality of life, and prevent disease progression and acute decompensations. According to a systematic review of 58 studies conducted by Dineen-Griffin and colleagues (2019), HF nurse specialists most commonly use the following interventions: 1) Providing knowledge about the condition, 2) Promoting lifestyle changes, 3) Developing self-care action plans, and 4) Enhancing problem-solving. Typically, standardized self-care action plans include the following recommendations (Heart & Stroke, 2018):

- Monitoring and recording daily weights;
- Watching for a weight increase of more than 2-3kg within one week;
- Understanding and monitoring symptoms
- Seeking support if changes to symptoms occur;
- Monitoring daily blood pressure and heart rate;
- Adhering to fluid restrictions;
- Checking for swelling in feet, ankles, leg, and stomach;
- Eating foods that are low in salt or salt-free;
- Taking multiple medications as prescribed;
- Balancing activity and rest periods.

The literature reports mixed results on the evaluation of HF clinics. On the one hand, certain studies suggest that these clinics decrease mortality, hospitalizations, and associated costs (Adlbrecht et al., 2010; Capomolla et al., 2002; Ditewig et al., 2010; Galbreath et al., 2004; Smith et al., 2008; Wakefield et al., 2013). On the other hand, some studies report no significant difference in effectiveness compared to usual care (Copeland et al., 2010; Kwok et al., 2008; Riegel et al., 2006; Wooton et al., 2009). Lambrinou and colleagues (2012) note that there is

inconsistency amongst HF clinics regarding interventions, intensity, settings, and length of follow-up and that this heterogeneity may contribute to unclear evidence. Evidence on self-care interventions is also unclear, with several studies suggesting that self-care interventions can decrease the chance of readmission (Atienza et al., 2004; Giordano et al., 2009). Yet, a systematic review conducted by Ditewig and colleagues (2010) found that self-care interventions did not always result in a significant reduction of hospital readmissions or improved quality of life. Interestingly, the most common outcomes measured in the literature tend to be system-related rather than patient-centred. These include mortality, hospital readmissions, costs, emergency department visits, and symptom management (Wakefield et al., 2013). When patient-reported outcome measures, such as quality of life, patient satisfaction, and self-efficacy, are considered, they are measured using standardized tools that produce a limited and narrow portrait of the patient's experience.

Although the heterogeneity of interventions may contribute to the unclear evidence around HF clinics, a small stream of research also notes that conceptual and theoretical issues may contribute to shortcomings in research and practice (Entwistle et al., 2018; Kendall et al., 2011; Paterson et al., 2001). For example, Greaney and Flaherty (2020) highlights an incongruence between the perception of providing holistic care and the biomedical focus of HF clinics, which may contribute to these shortcomings. Furthermore, the concept of self-care and how it has been taken up in HF clinics have been heavily influenced by medicine, psychology, and education. It is not well delineated within the discipline of nursing, despite how widely HF nurses use it and how influential it has been in shaping nursing practice in HF clinics. Finally, there is a growing concern that self-care interventions do not take into consideration the varying

factors that influence self-care, such as personal, social, cultural, contextual, and economic factors, as well as systemic and structural conditions (Kennedy et al., 2007).

The concept of self-care plays a central role in the HF literature and particularly in the nursing literature. Yet, the concept itself is rarely defined – thus creating a conceptual gap that has been largely overlooked over the years. For example, when Ditewig and colleagues (2010) conducted a systematic review of HF self-care interventions, they found that none of the included studies defined the actual concept of self-care used in HF management programs. Furthermore, although nursing has been theorizing and studying self-care since the 1950s, there is a wide range of definitions of the concept suggesting a lack of conceptual clarity. In fact, a content analysis by Godfrey and colleagues (2011) found 139 various definitions of the concept of self-care in the nursing literature published between 1970 and 2010. Moreover, the concept of self-care is often used interchangeably with self-management, self-monitoring, self-maintenance, and self-help, which creates further confusion (Riegel et al., 2019).

The uptake of the concept of self-care in nursing, and particularly in HF, has been somewhat uncritical. Self-care is rarely understood within a broader social, political, economic, and ideological context. This is an important gap because the concept of self-care is not neutral; it does reflect specific values, priorities, and orientations. For example, it tends to focus on individual behaviour to the detriment of social and structural determinants of health. It also shifts responsibility for the care and outcomes away from the health care system and onto the individual. In particular, self-care interventions are often used to limit healthcare costs associated with hospitalizations and emergency department visits (Entwistle et al., 2018; Greaney & Flaherty, 2020). By implementing these interventions, nurses may be unintentionally participating in interventions geared toward economic rather than patient-centred health goals

(Kendall et al., 2011). For all the reasons mentioned above, nurses must engage more critically and deeply with the concept of self-care.

For the purpose of this study, I opted to conduct an evolutionary concept analysis of self-care in the heart failure nursing literature. This type of analysis, at this particular point in time, is important because lack of conceptual clarity can potentially hinder optimal and desirable care by shaping how self-care support is implemented and evaluated. Understanding self-care in HF management not only specifies the role of nurses but also creates a basis for designing clinics and specialized care that are inclusive of patient and caregiver needs– as opposed to the health care system. Furthermore, due to the substantial influence from other disciplines on the concept, the embedded actions of nurses are often unrecognizable and undetectable when evaluating self-care outcomes. Consequently, despite the central role of nurses in establishing, launching, and running HF clinics, the work of nurses is often invisible and undervalued. If we are to understand, value, and properly evaluate the work of HF nurses, we must be able first to delineate key attributes of self-care support for HF management. From a research perspective, conducting a concept analysis of self-care specific to HF can expand the range of questions that drive nursing inquiries. It may further lead to theory development, which is needed from a nursing perspective to advance disciplinary knowledge and clinical practice in this area. In particular, uncovering neoliberal ideologies inherent in self-care support will render these assumptions open to debate and lead to developing critically oriented knowledge that can influence social, political, and economic policy and research (Browne, 2001). Neoliberalism is conceptualized by Ward and England (2007) as a complex underpinning macro-economic structure that encompasses: (i) policies and programs under the banner of privatization, deregulation, and liberalization; (ii) a type of reform that includes rolling back the welfare state

under the guise of cost-savings, and; (iii) a form of governmentality that encourages individual responsibility and promotes self-activation with an emphasis on individual calculability.

1.2 Research Objectives

- Explore the evolution of the concept of self-care in HF, including its philosophical and theoretical underpinnings;
- Identify and describe the antecedents, the attributes, and the consequences of the concept of self-care in HF;
- Critically analyze the uptake of the concept of self-care in heart failure and discuss the implications of the findings for nursing theory, research, policy, and practice.

1.3 Epistemological Position

Each research paradigm offers a way of understanding the world based on a set of ontological, epistemological, and methodological beliefs (Weaver & Olson, 2006). According to Guba and Lincoln (1994), the beliefs that define each paradigm can be summarized by the responses given to the three following fundamental questions:

- *The ontological question*

  What is the form and nature of reality, and what exists?

- *The epistemological question*

  What is the nature of the relationship between the inquirer, and what can be known?

- *The methodological question*

  How can the investigator go about discovering whatever they believe can be known?

This study draws on the critical theory paradigm to ensure that the concept of self-care in HF is analyzed and critiqued – its underpinnings and uptake questioned.

Ontologically, the critical theory paradigm maintains a position of historical realism (Weaver & Olson, 2006). In other words, it recognizes that reality is shaped by historical, social, political, cultural, and economic factors and other factors such as gender, race and class. These factors produce "a reality," but that reality is a construct that needs to be studied, uncovered, and deconstructed. Critical theory does not believe in universal truths. Instead, it adopts a critical stance towards the conditions of production of universal truths and emerging discourses (Weaver & Olson, 2006).

Epistemologically, the critical theory paradigm recognizes the relationship between the researcher, as the instrument of research, and the process of knowledge production: who knows, what can be known, how is knowledge produced and used, and so forth (Weaver & Olson, 2006, p. 462). According to Guba and Lincoln (1994), the researcher and the phenomena of interest are intimately connected, which means that the values, experiences, social location, and theoretical or philosophical orientations of the researcher will unavoidably shape the process of inquiry and, therefore, the product of inquiry.

From a methodological standpoint, critical theory locates and studies research problems within a broader social, political, economic, and ideological context (Weaver & Olson, 2006). As such, the research process includes not only the analysis of research data but also the analysis of that broader context. From this perspective, the goal of the research is to uncover forces at play in shaping the health and illness experience and influencing the delivery of care. Research can focus on gathering original data using qualitative interviews and observations. It can also focus on in-depth analysis of artifacts, texts, and images because critical theory sees the value in uncovering how inanimate "things" structure our actions, thoughts, and practices (Guba & Lincoln, 1994).

Locating this study in the critical theory paradigm is essential because this perspective pushes us to explore the concept of self-care in heart failure from a different standpoint – one that challenges the prevailing postpositivist standpoint, which currently dominates the scientific literature in the field. To my knowledge, although a small section of research has critically investigated self-care in chronic disease management (Jonsdottir, 2013; Kendall et al., 2011; Paterson et al., 2001), there has been no critical inquiry specifically exploring the concept of self-care in HF nursing. Therefore, framing this unique concept analysis from a critical theory perspective will address an important gap in the nursing literature and, more broadly, nursing practice. This perspective is essential to understand how nurses have come to adopt the concept of self-care in HF, how they use this concept in practice, how the concept shapes how care is delivered and evaluated, and how the concept has acquired meaning through its use over time.

CHAPTER 2

LITERATURE REVIEW

The following chapter is an overview of the literature on self-care, emphasizing self-care in the context of nursing and HF. I begin with a brief historical overview, followed by a review of the literature on self-care theory, research, and policy and practice.

2.1 Brief History of Self-Care

The concept of self-care is widely used in healthcare, and it now plays a central role in health education, health promotion, and chronic illness management programs (Lorig & Holman, 2003; Wilkinson & Whitehead, 2009). Its popularity has fluctuated over time, and its application has been far-reaching, resulting in conceptual complexity. The concept has acquired different meanings based on the social, economic, historical, and political contexts in which it was used – and who was using it. Suffice to say; context is paramount when studying self-care.

As early as the 1800s, self-care books were written for families who could not afford medical care and those who wanted to explore alternatives to medical care (Neuhauser, 2003). With the advent of scientific and medical discoveries in the early 20th century, there was less reliance on self-care and more emphasis on institutionalized biomedical care (Lorig & Holman, 2003; Morgan, 2020). However, shifts in medical interventions and disease patterns from acute to chronic conditions in the post-war era created circumstances whereby the focus shifted to chronic condition management (Denyes et al., 2001; Plews, 2005). The renewed interest in self-care to meet the increasing complexity and costs of chronic conditions in the mid-20th century coincided with the emergence of nursing as a discipline and its efforts to establish a legitimate and specialized knowledge base for professional practice (Northrup et al., 2004; Wilkinson & Whitehead, 2009). At the intersection between the need to develop nursing knowledge and the

renewed interest in self-care, nurse theorist Dorothea Orem developed her grand and middle-range theories on self-care in the late 1950s. These theories had a profound impact on the use and evolution of self-care in nursing. To this day, her work continues to be widely cited and informs nursing research, theory, education, and practice (McCormack, 2003; Younas, 2017).

2.2 Theorizing Self-Care in Nursing

The origins of self-care in nursing date back to Dorothea Orem's book entitled "*Guides for Developing Curricula for the Education of Practical Nurses,"* which was published in 1959. Orem's theorizing began as a master's project to formulate a definition of nursing and improve practical nursing training (Foster, 2011). Orem (1959) theorized that self-care is a daily action to maintain health and that self-care may need to be assisted with in particular circumstances, such as when a person is hospitalized or experiencing a period of illness. Orem identified these particular circumstances as moments when nursing care would be needed and contended that nurses act as "another self" when one cannot perform their own self-care (Foster, 2011). Orem continued developing the concepts of self-care and nursing care over the next decade. By 1971, she proposed a grand theory called "*The Self-Care Deficit Nursing Theory*" (Hartweg, 1991). By 1985, she had further articulated her grand theory and identified three underpinning middle-range theories, which are the theory of self-care, the theory of self-care deficit, and the theory of nursing systems (Orem, 1985). These interrelated theories differentiate the roles of individuals, nurses, and the circumstances when nursing care is required to achieve self-care goals (Orem & Taylor, 2011).

In 2008, Biggs conducted a literature review and found over 300 publications using Orem's self-care theories. It is safe to say that Orem's theories play an important role in shaping how nursing theorizes self-care (Attaallah et al., 2021; Baydoun et al., 2018; Dorsey &

Murdaugh, 2003; Pickett et al., 2014), studies self-care (Hartweg & Pickens, 2016; Khademian et al., 2020; Lacerda et al., 2019; Devi et al., 2012; Surucu & Kizilci, 2012), and uses self-care in practice (O'Shaghnessy, 2014; Reid et al., 1989; Seed & Torkelson, 2012; Tadaura et al., 2014; Timmins & Horan, 2007). Moreover, Orem's theories continue to serve as a foundation for nursing education and program curricula in Canada and internationally (Berbiglia, 2011; Clarke et al., 2009). The following sections provide a more detailed overview of Orem's grand theory and middle-range theories, as well as emerging self-care-related theories.

2.2.1 Orem's Theories of Self-Care

Orem's grand theory, the "*Self-Care Nursing Deficit Theory*," is composed of three interrelated middle-range theories: the theory of self-care; the theory of self-care deficit; and the theory of nursing systems (Denyes et al., 2001). The theory of self-care describes why and how people care for themselves. The theory of self-care deficit clarifies why and how people who face a deficit in self-care can be helped through nursing. The theory of nursing systems describes relationships between nurses and patients and explains how assistance provided by nurses can help patients meet self-care needs (Denyes et al., 2001). Together, her theories cover seven central concepts that are summarized in Table 2.1 (Foster, 2011).

Table 2.1 Relationship between Orem's concepts to the three theories (Foster, 2011)

Theory	Concept	Definition
Theory of Self-care	Self-care	The performance of activities that individuals initiate on their own behalf to maintain health, life, and well-being.
	Self-care requisites - Universal - Developmental - Health deviation	Universal: found across the lifespan and are involved with the maintenance of general well-being (i.e. intake of water and food, sufficient sleep, prevention of hazards) Developmental: Specific processes of growth and development throughout infancy into

		adulthood. Health deviation: Changes in human function that are out of normal range, which require diagnostic, therapeutic, and/or rehabilitative measures.
	Self-care agency	The ability for engaging in self-care, which is influenced by age, developmental state, life experience, sociocultural background, health, and available resources.
	Therapeutic self-care demand	The sum of deliberate actions that an individual performs to meet known self-care requisites. Therapeutic self-care demand may happen at an identified moment, or over an extended period of time.
Theory of self-care deficit	Self-care deficit	Nursing care is needed when therapeutic self-care demand is greater than self-care agency. This creates a self-care deficit. This self-care deficit can be addressed by nursing care. Five methods of helping are identified: 1. acting for and doing for others 2. guiding others 3. supporting another 4. providing a supporting environment 5. teaching another
Theory of nursing systems	Nursing agency	The power that the nurse has to engage in effective nursing practice for the benefit of individuals who have a self-care deficit.
	Nursing systems - Wholly compensatory - Partially compensatory - Supportive-educative	Wholly compensatory: When an individual is unable to carry out self-care actions and is dependent upon others to perform their self-care needs Partially compensatory: both nurse and patient are active in meeting patient's self-care needs and either may perform that majority of needed self-care Supportive-educative: Patient is fully capable of performing self-care activities, but needs some form of assistance such as gaining knowledge or skills to meet therapeutic self-care needs.

To sum up this section, it is important to point out that Orem's work is situated within the totality paradigm, which is rooted in positivism and post-positivism (Silva et al., 2009; Younas, 2017). Theories within the totality paradigm consider physiological, psychological, spiritual, and social well-being. However, they do so from an individualistic standpoint. They do not account for context, collective conceptualizations of care such as community care, or any structural factors that may impact health, illness, and the experience of taking care of oneself. As such, Orem's theories are philosophically underpinned by the belief that every person has the capacity and responsibility to care for and maintain their own health by engaging in self-care (Denyes et al., 2001; Attaallah et al., 2021). At the core, all patients are assumed to be self-reliant and responsible for self-care – and therefore capable of engaging in self-care and willing to receive self-care support if a deficit arises (Orem, 2001; Younas, 2017).

Orem's theories are also underpinned by a universalist (or essentialist) view, which assumes everyone shares the same self-care needs (Denyes et al., 2001). While Orem (2001) recognizes that both patient and nurse possess their own capacities, abilities, powers, values, and personal dispositions, the basic needs met by self-care are not considered unique per se. Orem (2001) considers that self-care is a deliberate and active process. Therefore, the nurse's role is to assist with self-care needs when a deficit arises and promote the development of self-care skills and capabilities (Younas, 2017). According to Orem (2001), education is one of the strategies nurses should use to promote self-care skills and capabilities. In other words, she sees knowledge as essential for promoting self-care and empowering patients to engage in self-care.

2.2.2 Theories of Self-Care Inspired by Orem

Since the 1990s, nursing scholars have been drawing on Orem's theories to develop middle-range and micro-range theories for specific patient populations, fields of practice, and health

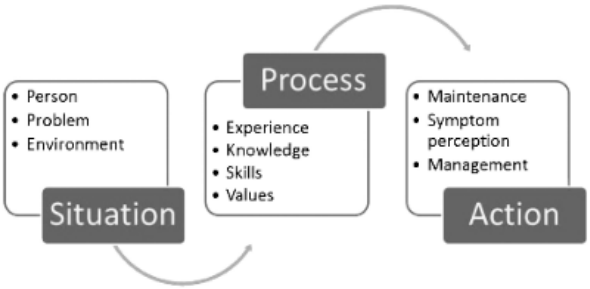
issues. In the field of HF, several theories have been underpinned by Orem's earlier works. For this chapter, I will focus on theories related to HF self-care and present each one in chronological order, from the earliest to the most recent.

2.2.2.1 Micro-Range (Situation-Specific) Theory of HF Self-Care

The micro-range (or situation-specific) theory of HF self-care was developed by Riegel and Dickson in 2008 to better describe self-care as "an essential ingredient in successful disease management" (p.190). They saw a need for this theory because self-care was poorly understood in HF and used interchangeably with other terms, such as self-management, self-regulation, adherence, and compliance. They sought to clarify self-care and related terms so that nurses could ultimately link theory, research, and clinical practice to guide both clinical interventions and research. They also sought to develop a theory that could contribute to better self-care and fewer self-care "failures," which, according to Riegel & Dickson (2008), contribute to repeated hospitalizations among HF patients.

According to this theory, HF self-care is a decision-making process that leads to three separate but linked actions that should be mastered in sequence (Riegel et al., 2016). The first is self-care maintenance, the second is symptom perception, and the third is self-care management. Self-care maintenance includes behaviours that maintain physiologic stability (Riegel et al., 2016). Examples of self-care maintenance include taking medications as prescribed, exercising, and following a sodium-restricted diet. Symptom perception involves monitoring for signs of change, recognizing and interpreting changes, and labelling symptoms (Riegel et al., 2016). Self-care management refers to the actions involved in responding to symptom changes when they occur. Figure 2.1 illustrates the factors influencing the actions described above.

Figure 2.1 Situation to process to action links (Riegel et al., 2016)



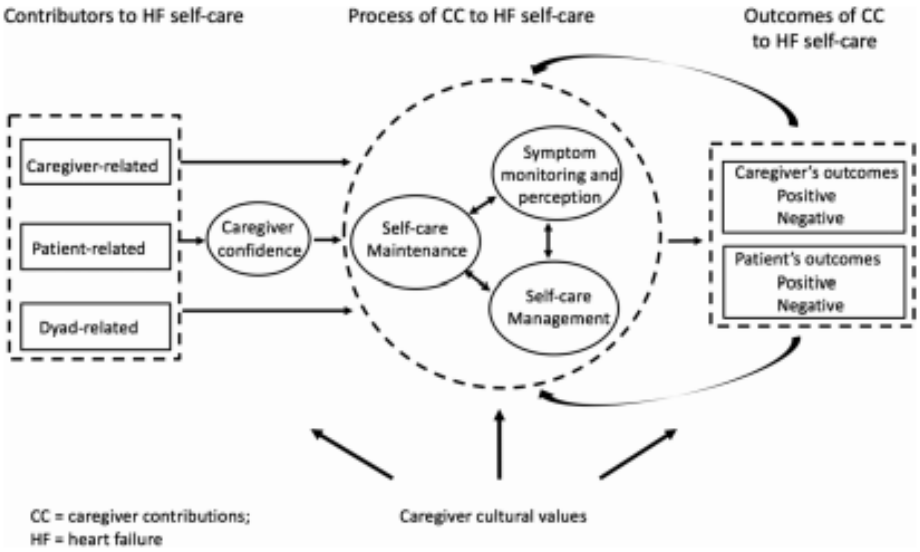
According to Riegel and colleagues (2016), several factors influence decision-making about self-care, including person-specific and environment-specific factors. Individual factors include experience, skills, knowledge, and values (Riegel et al., 2016). Environmental factors refer to the immediate environment, including living milieu and situation, and includes the relational aspects of self-care, such as having supportive caregivers that can support self-care actions (Riegel et al., 2016).

A strength of this theory is its ability to guide practice based on theoretical propositions (Riegel et al., 2016). For example, Riegel and colleagues (2016) propose that "self-care is influenced by knowledge, experience, skills, and compatibility with values" (p.231). Understanding this proposition, for example, is important for nurses working in HF clinics because they tend to work with a standardized list of self-care actions and need to be reminded that each patient has a unique set of knowledge, experience, skills, and values. Furthermore, Riegel et al. (2016) theory has contributed to the advancement of HF research. Between 2008 and 2016, it was utilized in eighty-five published articles (Riegel et al., 2016). One limitation of this theory is its biomedical and individual focus (Riegel & Dickson, 2008). Another limitation is the narrow understanding of the environment and failure to include broader social and structural determinants of health – thus missing important factors that shape self-care in HF.

2.2.2.2 Micro-Range (Situation-Specific) Theory of Caregiver Contribution to HF Self-care

In 2019, Vellone and colleagues developed a theory to shed light on the role of caregivers in supporting people living with HF in their self-care activities (see Figure 2.2). They define the caregiver contribution to HF self-care as "the provision of time, effort, and support on behalf of another person who needs to perform heart failure self-care" (p.167). Vellone and colleagues (2019) found that caregivers mirrored the actions described in the situation-specific theory of HF self-care (i.e., self-care maintenance, symptom perception, and self-care management). However, they were considered a substitute in situations where the person living with HF cannot perform the activity independently.

Figure 2.2 Theory of caregiver contribution to HF self-care (Vellone et al., 2019)



This situation-specific theory depicts the caregiver contribution to HF self-care, which is influenced by caregiver-related factors, patient-related factors, and dyad-related factors. It also explains that the caregiver can contribute to symptom monitoring and perception, self-care maintenance, and self-care management in ways that lead to positive or negative outcomes

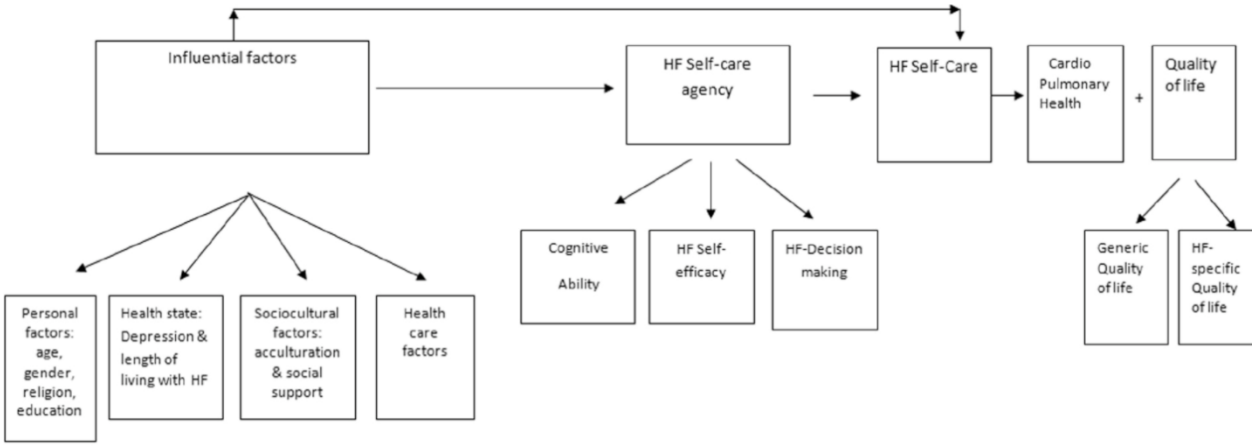
(Vellone et al., 2019). Vellone and colleagues (2019) note that caregiver contribution may increase based on patient-related factors, such as low cognition, low education levels, or low physical capacity (Vellone et al., 2019). An interesting feature of the theory is the inclusion of dyadic factors such as the quality of the relationship between the caregiver and the person living with HF (the patient) and the nature of the relationship (i.e., spouse, child, relative). For example, is there shared decision-making self-care actions and lifestyle changes? What is the communication style? Does the nature of the relationship help or hinder self-care? (Vellone et al., 2019). In this theory, knowledge and skills about heart failure management for both the caregiver and the patient are considered key to mastering self-care. Therefore, increasing knowledge and skills is necessary to improve the contribution of the caregiver and in turn, the self-care (Vellone et al., 2019).

A strength of this theory is that it conceptualizes self-care as a dyadic phenomenon, and in doing so, it addresses the limitations of other theories that consider self-care as an individual process (Vellone et al., 2019). Another strength is the contribution of this theory to the advancement of research and practice. For example, a caregiver contribution to self-care of HF index measurement tool has recently been developed by Vellone and colleagues (2021). A limitation of this theory is the lack of acknowledgement of cultural and familial expectations around caregiving. Vellone and colleagues (2019) note that not all patients want the attention of their caregivers and that cultural and familial obligations for caregiving are not universal. Furthermore, although relational aspects between caregivers and patients are considered, there is no explicit discussion of personal factors impacting the dyad dynamic such as gender.

2.2.2.3 Middle-Range Theory of HF Self-care

Attallah and colleagues published a middle-range theory of HF self-care in 2021 with the specific goal of addressing the limitations of the theories described above. As noted by Attallah and colleagues (2021), Riegel and colleagues' theory "limits an understanding of self-care as a process of making decisions before taking actions" (p. 169). They argue that the situation-specific theory of HF self-care is too narrow and only includes some HF self-care behaviours. For example, sociocultural and healthcare system factors are not included within Riegel and colleagues' theory, and the theory does not capture all of the relevant concepts needed to explain HF self-care (Attallah et al., 2021). Drawing on these gaps, the middle-range theory developed by Attallah and colleagues was to create a theoretical framework that addresses all the elements needed to move from HF self-care decision to action. It includes influential factors related to the person (the patient) and their health state as well as macro-level factors such as sociocultural and health care factors. To my knowledge, this is the only HF nursing theory that addresses some of the macro-level factors that affect HF self-care.

Figure 2.3 Theory of HF self-care (Attallah et al., 2021)



The theory includes four main concepts: 1) influential factors, 2) HF self-care agency, 3) HF self-care, and 4) heart failure self-care outcomes (Attallah et al., 2021). The influential

factors are defined as circumstances and conditions that influence an individual's ability to meet HF self-care demands, which, as mentioned above, include personal factors, health state factors, sociocultural factors, and healthcare system factors (Attallah et al., 2021). HF self-care agency refers to the person's cognitive capacity, self-efficacy, and capacity for decision-making (Attallah et al., 2021). In turn, self-care agency influences HF self-care, which includes the actions that a person performs to meet their HF self-care (Attallah et al., 2021). Self-care is the necessary actions that are part of living with HF, such as daily weighing, adhering to a low sodium diet, and adhering to a medication regimen (Attallah et al., 2021). Finally, HF self-care outcomes include objective outcomes, such as improved heart rate, blood pressure, and euvolemic fluid status, and subjective outcomes, such as improved quality of life (Attallah et al., 2021).

The middle-range theory of HF self-care is strengthened by the authors' synthesis and identification of gaps in theoretical literature on HF self-care. It is less narrow than previously published micro-range (or situation-specific theories) on HF self-care and includes complex elements that influence self-care actions. Furthermore, according to Attallah and colleagues (2021), the theory is designed to be empirically tested. However, limitations of this theory exist. Although health care influences are included, there is a need for more detail and nuance. For example, the only health care factors acknowledged within the theory included insurance costs, having ethnically congruent healthcare providers, and having access to resources in the individuals' native language (Attallah et al., 2021). There is no mention of how healthcare providers or the system itself can best support HF self-care, nor are there ideal system-level interventions to support HF self-care. Furthermore, while cognitive capabilities and self-efficacy

are deemed essential to HF self-care, there is no discussion of what nurses should do if these factors are not present.

2.2.3 Other Influences on Self-Care

Although Orem's theories have heavily influenced much of nursing's conceptualization of self-care, it is important to note other theoretical influences outside of nursing that have shaped our understanding of self-care. For this chapter, I will only briefly summarize the influence of theories derived from psychology and medicine. I will also touch on self-care in popular culture. The goal is not to offer a comprehensive review of each theory but rather to acknowledge other (non-nursing) influences on the self-care literature and HF nursing.

Psychology. The most commonly cited theories in the self-care literature arise from psychology and, more specifically, behaviour change theory, including social learning theory and self-determination theory. These theories situate self-care within the person and their motivation, perceptions, knowledge, and so forth.

Bandura's (1977) social learning theory has been used to understand self-care behaviours, including the interaction between such behaviours and personal or environmental factors. According to Bandura (1997), self-efficacy is a prerequisite for self-care. In other words, a person perceiving and believing in their ability to perform self-care is the first step toward performing self-care. Bandura's (1997) theory has influenced nursing science (Eller et al., 2018; Ludman et al., 2013) and, more specifically, HF nursing care (Chen et al., 2014).

Self-determination theory is a motivational theory used to enhance self-care (Vansteenkiste et al., 2006). This theory posits that determination to engage in self-care is influenced by internal and external motivations. Internal motivations arise when people see value in engaging in a self-care activity to satisfy their needs (Johnson, 2007). The motivation comes

from within; hence why it is called self-regulation. Self-regulation is commonly discussed within the nursing HF literature. For example, self-regulation underpins motivational interviewing interventions, widely used to promote HF self-care (Johnson, 2007; Vansteenkiste et al., 2006).

Behavioural Medicine. Self-management is the most commonly used synonym for self-care in medicine – and nursing (Riegel & Dickson, 2008). The origins of self-management can be traced back to Thomas Creer and his work in behavioural medicine (Lorig & Holman, 2003). In the 1960s, Creer and his colleagues coined the term self-management to describe patients who were actively involved in their treatment (Lorig & Holman, 2003). Self-management now mainly refers to the educational and supportive interventions that are delivered within chronic disease programs (Kendall et al., 2011). According to a concept clarification by Richard and Shea (2011), self-care is a broad concept that subsumes self-management; however, the relationship between the two concepts is not always clear.

Popular culture. The concept of self-care has been used by various groups and for various purposes over the past decades. For example, feminists used the concept in the 1970s to advocate for autonomy (including bodily autonomy), self-determination, and independence from the patriarchy and medicine (Kickbusch, 1989). Over time, an uptake of self-care in popular culture was seen to market products, create new self-care industries, and generate profits (Rennis et al., 2015). Self-care also became a way of encouraging neoliberal approaches to personal health and decreasing health care spending (DeFriese et al., 1989). By the 1980s, self-care was synonymous with a "healthy lifestyle" and positively associated with health promotion and disease prevention (DeFriese et al., 1989). These days, the concept of self-care is experiencing heightened popularity, but its meaning, purpose, and use are closely tied to context. From the wellness

industry to radical activism, this concept is now part of our everyday discourse, which further justifies the need to clarify what we mean when we use self-care in the context of HF.

2.3 Research on Self-Care in HF

Just as with self-care theory, self-care research in nursing is broad and encompasses acute and chronic care. Self-care research includes studies from the perspective of the nurse, the patient, and the healthcare system. It also covers wide range of health conditions. Given that the focus of this thesis is on self-care in HF, this section will summarize the HF self-care research exclusively and will cover three themes presented in order of importance in the literature:

1. Individual self-care
2. Relational self-care
3. Social and structural determinants of self-care

2.3.1 Individual Self-Care

Unsurprisingly, the majority of research on HF self-care is limited to the individual level. This section outlines the literature on self-care interventions, followed by self-care measurement tools.

Self-care interventions. In 2017, Cavalcante and colleagues published an integrative review of self-care behaviours in HF. They found several distinct behaviours required to achieve optimal self-care in HF (see Figure 2.4). These behaviours – all individual in nature and focus – indicate the type of research conducted on HF self-care to date.

Figure 2.4 Concepts related to the self-care process (Cavalcante et al., 2017)

Interventions to promote behaviour change, regardless of the area of focus above, can be grouped into the three following categories: 1) increasing knowledge, 2) increasing motivation, and 3) providing practical tools (Jaarsma et al., 2012). Interventions to increase knowledge include education to increase factual knowledge, improve the application of knowledge, and encourage patients to take responsibility for their behaviour change (Jaarsma et al., 2012). Interventions to increase motivation include implementing communication strategies (such as motivational interviewing), creating collaborative relationships, and encouraging patient autonomy (Jaarsma et al., 2012). Interventions to provide practical tools seek to encourage people living with HF to journal their symptoms, document their sodium intake, for example, and track their treatment adherence (Jaarsma et al., 2012). Technology, such as telehealth and monitoring devices, have also been developed and tested in HF research (Inglis et al., 2017).

Interventions to increase knowledge are underpinned by the idea that self-care is a learned process and that increasing knowledge about HF will enable individuals to perform better self-care. A systematic review by Ruppar et al. (2015) found that these interventions predominantly focus on providing education about HF and treatment adherence. Research tends to focus on two domains: pre-intervention and intervention. Pre-intervention research focuses on the need to assess self-care levels and knowledge gaps, whereas the intervention research focuses on the development, testing, and implementation of interventions (Boisvert et al., 2015; Boyde et al., 2013; Boyde et al., 2018; Clark et al., 2015; Jaarsma et al., 2000; Lupon et al., 2008; Rodriguez-Gazquez et al., 2012). A wide range of nursing interventions have been studied in the literature, including patient education activities, interventions targeting caregiver education, programs to increase activity levels, and technology to enhance comprehension (Clark et al., 2015; Deek et al., 2016; Son et al., 2020). The following three examples are helpful to show the range of interventions studied to date: 1) Clark and colleagues (2015) created multiple educational modules that HF nurse specialists delivered to patients, 2) Gary and colleagues (2020) combined a 12-week home-based walking program with computerized cognitive training to improve self-care behaviours, and 3) Rodriguez-Gazquez and colleagues (2012) studied ways of including the family in educational activities and developed low literacy print materials.

There is no consensus in the literature regarding the best interventions; however, Bryant and colleagues (2017) found in a systematic review of 29 HF self-care interventions that most studies included one-on-one educational approaches with supplementary print or digital materials and telephone interactions. It is important to note here that low health literacy levels have been reported in the HF literature, which suggests additional challenges in developing print and digital materials that meet the patients' needs. In their study, Cajita and colleagues (2016) found that

39% of heart failure patients had low health literacy levels. Interestingly, Chen and colleagues (2014) found that health literacy influenced knowledge about HF but not actual self-care behaviours. Nevertheless, recommendations remain that nurses should adopt strategies to address low health literacy so that patients can perform better self-care (Cajita et al., 2016).

When used alone, interventions to increase knowledge are ineffective at improving HF self-care (Dionne-Odom et al., 2016). For this reason, there is a body of research on interventions aimed at motivation. This research stems from the understanding that behaviour change is influenced by psychological factors (such as self-efficacy and self-regulation), emotional, and cognitive factors (Chew et al., 2019; Dionne-Odom et al., 2016). Nursing interventions related to motivation seek to support patients in achieving optimal self-care via internal and external influences that play a role in behaviour change (Paradis et al., 2010). For example, a systematic review by Jiang and colleagues (2018) found that incorporating psychological techniques, such as motivational interviewing and cognitive behavioural therapy, improved self-care in patients without depression and cognitive impairment. Motivation-enhancing interventions are less commonly cited in the literature compared to educational interventions. The reason remains unclear, but in their integrative literature review, Boisvert and colleagues (2015) found that HF nurses considered motivation-enhancing interventions less than half of the time compared to educational interventions (included all of the time).

Interventions to incorporate practical tools are another area of HF research. Tools to support self-care activities and increase adherence include medication dosing boxes, using alarms and schedules to take medications, and providing patients with journals to log daily symptoms (Jaarsma et al., 2012). Other interventions include encouraging patients to buy home scales and blood pressure monitors (Jaarsma et al., 2012; Mehta et al., 2020). HF action plans are

another tool to assist patients in implementing self-care activities, such as recognizing symptoms and knowing what to do should they occur (Anderson et al., 2021). In recent years, researchers have turned to technology to explore new tools to support self-care and, most importantly, self-care adherence. These include wearable devices, smartphone apps, telehealth monitoring, and remote monitoring devices to collect, record, and transmit health data (Greenhalgh et al., 2017; Maeder et al., 2015; Mehta et al., 2020; Mortara et al., 2020). These tools are considered promising for patients who have signs of deterioration before seeking healthcare attention (Ciere et al., 2012). They also have positive results in reducing hospitalizations and avoiding costly medical care (Radhakrishnan et al., 2012).

Self-care measurement tools. The development and evaluation of self-care measurement instruments are an important part of HF research. Measuring self-care is commonly done with scales, such as the:

- Self-Care of Heart Failure Index (Riegel et al., 2004)
- European Heart Failure Self-care Behaviour Scale (Jaarsma et al., 2003, 2009)
- Heart Failure Compliance Questionnaire (Evangelista et al., 2001)
- Stanford Heart Failure Food Intake Checklist (DeBusk, 1996)
- Dietary Sodium Restriction Questionnaire (Bentley et al, 2009)
- Dutch Heart Failure Knowledge Scale (van der Wal, 2005)
- Kansas City Cardiomyopathy Questionaire (Green et al., 2000)

The Self-Care of Heart Failure Index (SCHFI) is one of the most common scales used in HF research, and it measures behaviours that are recommended by the European and American Heart Failure Guidelines (Vellone et al., 2013). The SCHFI captures three dimensions of self-care, including maintenance, management, and confidence. The higher the score on these scales, the

more adherent to treatment and adherent to self-care behaviours (Vellone et al., 2013). Self-care maintenance has ten items that measure monitoring and adherence behaviours performed to prevent heart failure exacerbations, such as monitoring weight, eating low-salt diets, and taking medication (Vellone et al., 2013). Self-care management includes six items that measure the ability to recognize and respond to symptoms when they happen, such as consulting a provider, reducing fluid intake, and taking extra diuretics (Vellone et al., 2013). Finally, self-care confidence includes six items to evaluate the perceived ability to engage in the self-care process (Vellone et al., 2013). The SCHFI has been used extensively in the literature. The SCHFI is often used to evaluate the effectiveness of self-care interventions and examine relationships between self-care and various influencing factors (Evangelista et al., 2015; Lee et al., 2019; Massouh et al., 2020).

2.3.2 Relational Self-Care

Self-care tends to be conceptualized as an individual process (Bidwell et al., 2015). For this reason, the body of literature on the relational aspects of self-care is relatively small. However, in recent years there has been increased interest in and recognition of relational factors, including the role of caregivers and healthcare providers. Informal caregivers include family, friends, or neighbours (Buck et al., 2014), whereas formal caregivers are typically healthcare providers working in the community and acute care settings (Kitko et al., 2020).

Caregivers. In a recent qualitative systematic review of 21 articles, Whitehead and colleagues (2018) found that caregivers play an important role in supporting HF self-care. These undertakings include sharing responsibility, whole family involvement, promoting social interaction, performing day-to-day tasks that promote self-care, finding balance, and evolving family roles over time (Whitehead et al., 2018). Spouses are often the primary caregivers, but

that role may be filled by a child, a relative, or a friend. According to Dunbar and colleagues (2008), there has been an ever-growing body of evidence to support the association between caregiver support and better self-care outcomes. In contrast, social isolation and the absence of caregiver support have been shown to increase HF mortality and morbidity (Friedmann et al., 2006). Caregiver contribution to self-care can vary based on knowledge, cognition, relationship type and quality, caregiver strain, and perceived supports (Bidwell et al., 2018; Bidwell et al., 2015). In qualitative research, informal caregivers have spoken about their contributions and how they see them as valuable in achieving HF self-care. In their work, Cameron and colleagues (2016) found that caregivers emphasized the importance of self-care and believed they could provide emotional support, encouragement and organize routines to support self-care.

Healthcare providers. Healthcare providers play an important role in supporting self-care through various interventions mentioned above. There is frequent recognition within the literature that implementing self-care behaviour change is complex, and healthcare providers should support self-care mastery. However, most research focuses on the activities necessary to achieve self-care, with significantly less acknowledgement of the healthcare providers' influence on self-care. Although interventions to meet self-care demands are influenced by the healthcare providers who deliver said interventions, the research reviewed infrequently notes this influence.

Healthcare providers can have a positive or negative impact on self-care practices. Several factors are associated with a positive impact, such as communication and listening skills, stable care teams fostering continuity of care, trust, and respect (Currie et al., 2015; Peng, 2015; Woda et al., 2012). Among the factors that can result in a negative impact, researchers found that a lack of knowledge, insufficient support, poor communication, and judgmental attitudes can be detrimental to self-care (Harkness et al., 2015). Studies have also documented situations in which

healthcare providers lack expertise in self-care and do not provide support when required, causing patients to discontinue their monitoring and delay seeking care (Andersson et al., 2012; Oxberry et al., 2012; Woda et al., 2015). Research suggests that poor communication and language barriers can make it difficult for patients to understand self-care instructions (Andersson et al., 2012; Gallacher et al., 2011). Furthermore, research suggests that healthcare providers need to be proactive in offering self-care information to avoid patients feeling that they are not getting all the information they need or have to be overly assertive to get support (Hopp et al., 2012).

2.3.3 Self-Care in Healthcare Systems

The role of the healthcare system is rarely overtly acknowledged in the HF self-care literature. However, the most commonly cited rationales for self-care interventions are decreasing hospitalizations and cutting costs associated with HF exacerbations. In other words, self-care is rationalized for system-level objectives, yet is overwhelmingly described as an individual intervention. There is a body of research focusing on the cost-effectiveness of self-care for this reason (Lee et al., 2007; Reilly et al., 2015; Stewart et al., 2002). Yet, as Butler and Kalogeroplous (2012) point out, the evidence remains virtually non-existent that current self-care interventions (which focus almost exclusively on the patient) are most effective at addressing the root causes of repeated hospitalizations and rising health care costs related to HF – such as social and structural determinants of health.

Social and structural determinants of health impact self-care, but they tend to be overlooked in the literature on HF. The social determinants of health encompass the full set of social conditions in which people live and work, whereas the structural determinants of health are the structural mechanisms in place (ie: public institutions, government and social policies,

societal values) that affect the social determinants of health and shape health outcomes (World Health Organization, 2010). I include a few examples of studies here to illustrate why this gap is problematic. Low socioeconomic status is considered a powerful independent predictor of HF development and progression (Hawkins et al., 2012). In their systematic literature review, for example, Hawkins and colleagues (2012) found that lower socioeconomic status was independently associated with developing HF and subsequently being readmitted to hospital more frequently. Yet, issues related to income, housing, employment, health care coverage, and so forth are not included in self-care interventions. The same is true for race and culture. Self-care behaviours pertaining to diet, for example, are primarily based on a Western white middle-class diet, and recommendations may not be compatible with food preferences and habits among communities Black, Indigenous, and People of Color (Dickson et al., 2015). Cultural safety, tailoring of dietary recommendations, and access to food are also not discussed in self-care interventions. Generally speaking, there is little attention in self-care research on the immediate and broader environment in which a person (and their family) experiences HF (Dickens et al., 2019). For example, Dickens and colleagues (2019) recommend assessing stressors so that appropriate supports can be provided as part of self-care interventions. Along the same lines, Jaarsma and colleagues (2012) have called for barriers to HF care to be better addressed to create conditions in which self-care is even possible. Finally, gender should also be considered when it comes to the experience of HF, self-care, and social roles (including caregiver roles). (Abe et al., 2019; Bidwell et al., 2015; Graven et al., 2019; Lee et al., 2011). Research on the relationship between gender and self-care has drawn mixed conclusions, and many gaps remain to adapt self-care interventions which tend to rely heavily on a (male) gendered experience of HF and (female) gendered support in the form of spousal support.

2.4 Self-Care in Policy and Practice

The implementation of self-care interventions in practice has been influenced by theory and research. However, policy and practice documents have also played an important role. The following sections highlight the policy milestones related to self-care practice and introduce the guidance documents that currently support nursing practice in HF clinics.

2.4.1 Self-Care Policy

In Canada, the Lalonde report (1974) created the groundwork for a major transition in the conceptualization of health and the delivery of care (McCormack, 2003). The Lalonde report (1974) was published when governments were becoming increasingly concerned with chronic illnesses and associated costs of an ageing population. It signalled an important shift away from hospital care to lifestyle changes and healthy behaviours. This paradigm shift created the space for self-care initiatives to proliferate (McCormack, 2003). In 1986, the Federal Minister of Health, Jake Epp, created a health policy document that recognized self-care as an intervention to address blossoming health challenges (McCormack, 2003). Self-care was defined by Epp (1986) as the "decisions and actions individuals take in the interest of their own health" (p.7), and self-care thus became a central component of the national framework for health promotion (McCormack, 2003). A decade later, a conceptual framework for supporting self-care initiatives was developed by Health Canada. The framework included five interacting components: supporting the person, sharing knowledge, facilitating learning and personal development, helping the person build supportive networks, and providing a supportive environment (Health Canada, 1997). A supportive environment was described as a healthcare system where patients can easily access services when needed to solve problems and attend to health needs (Health

Canada, 1997). Together, these three policy documents created the path for developing self-care initiatives across various chronic conditions, including HF.

2.4.2 Self-Care in Practice

Several guiding documents for HF practice exist in Canada. The Canadian Cardiovascular Society (CCS) and the affiliated Canadian Heart Failure Society (CHFS) strive to provide practical guidance for healthcare professionals, including nurses, across Canada to improve practice and care delivery when managing HF (CHFS, 2019). The CCS (2016) defines self-care as the "behaviours necessary to maintain or promote health and lifestyle changes and manage the symptoms and effects of living with HF" (p. 307). The CCS Heart Failure Companion further clarifies the elements of HF self-care, as depicted in Table 2.2.

Table 2.2. The elements of HF self-care, according to CCS guidelines (CCS, 2016)

Self-care Terms	Associated Activities
Self-care maintenance	Behaviours that adhere to recommendations, including dietary changes, taking medication as prescribed, and exercising regularly
Self-care monitoring	Daily activities to monitor for HF symptoms and recognize when a change occurs
Self-care management	Determine what action is needed when changes in symptoms occurs

The CCS (2016) guidelines for optimizing self-care in patients with HF include both individual and relational elements. At the individual level, the CCS (2016) recommends strategies to improve confidence, such as counselling to overcome self-care barriers, reinforcing positive behaviours, and setting realistic goals. The guidelines also recommend screening for anxiety, depression, cognitive impairment, and literacy levels (CCS, 2016). From a relational perspective, CCS (2016) recommends involving information and formal caregivers and including additional community resources when support systems are insufficient. Healthcare providers are

also encouraged to personalize education to help patients decipher their own early signs of HF decompensation (CCS, 2016). Emphasis is placed on the importance of enhancing self-care skill development and learning over time. As such, healthcare providers are encouraged to implement evidence-based interventions such as cognitive-behavioural strategies, teach-back techniques, and problem-solving development (CCS, 2016). The 2017 CCS updated guidelines further clarified that self-care interventions can be provided during in-person visits or delivered by telephone or with other forms of technology.

In 2020, the CHFS and CCS assessed the current state of HF clinics across Canada and the implementation of HF guidelines. They found that the following supportive interventions were being implemented across Canadian HF clinics: optimization of heart failure medical therapies (97.6%); medication support and counselling (95.1%); medication reconciliation (87.8%); dietary nutrition counselling (85.4%); involve patients in shared decision making (80.5%); advanced care and end of life planning (78%); self-management services and resources (73.2%); education sessions (68.3%); exercising training and support (68.3%); smoking cessation program (36.6%); counselling services (34.1%); online tools and education (31.7%); influenza vaccinations (29.3%); patient support group (12.2%); and caregiver support group (4.9%) (Virani et al., 2020). Furthermore, they found that 98% of HF clinics across Canada offered nursing support by telephone and noted that nurses were responsible for a large portion of patient education after initial consultation with a cardiologist (Virani et al., 2020).

In summary, the above literature highlighted HF self-care in theory, research, and practice. I began with a brief historical overview of self-care, followed by a more extensive summary of self-care theorizing in nursing. I focused on Orem's theories of self-care, followed by HF-specific theories derived from Orem's work. I also noted other influences on self-care

theory from psychology, behavioural medicine, and popular culture. To summarize the research on HF self-care, I categorized the literature in order of coverage in the literature, starting with individual-focused research, to relational-focused research, and finally, research exploring social and structural determinants of self-care. I also pointed to an overemphasis on the individual to the detriment of other factors needed to understand self-care in context and relationships. Finally, I presented self-care in policy and practice by identifying the guiding documents that shape self-care in HF practice. Across all three sections of this chapter, self-care is rarely (if ever) considered beyond the individual and their immediate support. Furthermore, the concept of self-care, although important in nursing and HF, was infrequently clarified and described in the reviewed literature. In light of these gaps, it is crucial to carry out a concept analysis on self-care in HF and critically analyze the uptake of self-care in heart failure nursing. This can provide a path forward to improving patient outcomes, HF care and providing truly patient-centred nursing care.

CHAPTER 3

METHODOLOGICAL CONSIDERATIONS

The following chapter is an overview of the methodological considerations for this study. In the first section, I describe concept analysis, explain its origins in nursing, and summarize the three different schools of thought. In the second section, I offer a detailed overview of the chosen approach for this study, Rodger's (2000) evolutionary approach, and the research process, including data sampling, collection, and analysis.

3.1 Concept Analysis

By virtue of their role in knowledge development and advancement, nurse scholars must grapple with concepts - including what they are, their contribution to the discipline, and how concepts are instrumental in developing theoretical and empirical knowledge. Despite the diversity of perspectives on concepts, there is a "consensus that concepts are cognitive in nature and comprised of attributes abstracted from reality, expressed in some form and utilized for some common purpose" (Rodgers, 2000, p.33). There is also a clear agreement across disciplines that an important relationship exists between concepts and knowledge (Rodgers, 2000). In fact, the identification, clarification, development, and maturation of concepts are vital steps of disciplinary progress because concepts have the power to shape what and how a discipline understands, researches, and theorizes, as well as the power to frame and guide professional practice. For professional disciplines like nursing, concepts are critical in shaping the role of nurses and subsequently impact how care is delivered.

Concept analysis is a rigorous inquiry that further clarifies and develops concepts to advance disciplinary knowledge in theory, research, education, and clinical practice. A concept analysis seeks to dissect a concept into distinct elements to promote clarity and mutual

understanding within a disciplinary context (Meleis, 2007). Concepts function as labels to explain or give meaning to phenomena of interest to a discipline. A concept is not merely a word with a corresponding definition; it provides order to observations and experiences and enhances understanding of situations and events (Meleis, 2007). For example, comfort has been a concept of interest in nursing and a goal of nursing care since Florence Nightingale. The concept of comfort gives meaning to aspects of nurses' work in practice. However, the comfort work of nurses is often so embedded into practice that its key attributes are often not recognized or acknowledged (Oliveira, 2013). This can result in the undervaluing of comfort work, for example.

It is challenging to advance theory, research or practice when a concept is vague, imprecise, or lacking clarity. Nurses may use different labels or language when referring to the same concept, leading to incongruities within disciplinary theory and research. Advancing disciplinary research and theory requires a certain level of precision. Given that concepts are foundational labels to build disciplinary knowledge, it is essential to understand and clarify the language we use to describe phenomena of interest to the discipline. As such, concept analysis can be used as a methodological approach to provide clarity, guidance, and understanding to a concept of interest to the discipline of nursing when a concept is vague, not clearly understood, or when research and practice do not align. Concept analysis can contribute to disciplinary understanding by guiding researchers in the formulation and clarification of a mental construct, systematization of relevant information, and breaking down and building up its various components and attributes (Weaver & Mitcham, 2008).

Concept analysis is different from concept exploration and clarification. Concept exploration is a strategy for concept development when a new concept exists but is not yet an

accepted component of the nursing discipline. In contrast, concept clarification seeks to refine concepts used in the nursing discipline that lack explicit, shared, or agreement on the properties of said concepts (Meleis, 2007). Concept analysis focuses on concepts that have already been introduced and delineated within the disciplinary literature but are analyzed to advance research, theory, and clinical practice.

3.2 Concept Analysis in Nursing

Over the 20th century, nurses put considerable effort into developing a unique body of knowledge as a discipline. Engaging in conceptual work became a necessary step to establish, legitimize, and differentiate the theoretical and empirical foundations of the discipline (Weaver & Mitcham, 2008). Concept analysis methodologies were initially borrowed from other disciplines, including sociology, education, and psychology (Rodgers, 2000). Nursing-specific methodologies were introduced in the early 1980s (Rodgers & Knafl, 2000). Walker and Avant developed the first concept analysis approach for the nursing discipline in 1983, followed by Chinn and Jacobs (now Kramer) that same year. Schwartz-Barcott and Kim developed another variation on the concept analysis approach in 1986, followed by Rodgers in 1989.

Concept analysis in nursing is now recognized as a stand-alone research approach that can contribute to knowledge development for both theory and research (Hupcey & Penrod, 2005). Concept analysis methodologies can create a strong foundation for theory and research to advance the discipline because they clarify and delineate concepts that are the basis of nursing disciplinary knowledge. Nurse scholars have used concept analysis methodologies to analyze concepts such as caring (Brilowski & Wendler, 2005), surveillance (Kelly & Vincent, 2011), resilience (Ahern, 2006), death anxiety (Lehto & Stein, 2009), adherence (Bissonnette, 2008), mindfulness in nursing (White, 2013), professionalism (Ghadirian et al., 2014), and compassion

fatigue (Sorenson et al., 2017). Furthermore, Rodgers' evolutionary approach has been used from a critical theory perspective to analyze concepts including whistleblowing (Gagnon & Perron, 2020), empowerment (Dooher & Byrt, 2020), and HIV viral load (Gagnon & Guta, 2014).

3.3 Philosophical Underpinnings

There are two primary schools of thought to concept analysis: entity and dispositional (Rodgers & Knafl, 2000). Distinct philosophical underpinnings support each one. On the one hand, the entity approach views concepts as "things" and seeks to discover the universal essence (definition) of concepts (Rodgers & Knafl, 2000). On the other hand, the dispositional approach views concepts as having explanatory power to describe behaviours or phenomena, but there is a general acceptance that boundaries of concepts may be fuzzy. A clear picture may not be attainable nor desirable because concepts are continually changed, refined, and enhanced (Rodgers & Knafl, 2000). A dispositional approach believes that many factors including time and context, influence concepts (Rodgers & Knafl, 2000). In other words, there is an understanding that concepts evolve, acquire meaning over time and are dependent upon contexts. Unlike an entity approach, a dispositional approach does not believe in a core, universal essence (definition), nor does it aim to discover universal truth. Key characteristics of the entity and dispositional approaches are summarized in Table 3.1.

Table 3.1 Characteristics of entity versus dispositional approaches (Rodgers, 2000)

Entity	Dispositional
• Universal essence, unchanging over time and across contexts • Abstract ideas in the mind that match an actual element of reality • Set of necessary and sufficient conditions to define a concept	• Possess explanatory power demonstrated by their utility in characterizing phenomena or situations of interest • Emphasis on the use of the concept and the behaviours that they make possible • Influenced by various factors, including time and context

• Critical conditions or attributes necessary to define the concept and distinguish it clearly from all other concepts • Boundaries of each concept are clearly delineated, static in nature, and can be viewed in isolation.	• Not an absolute determinant of truth • Not dependent upon core or essential attributes • Not reasonable to expect a perfectly clear picture of all concepts • Concepts are continually changed, refined, or new concepts are introduced to enhance the problem-solving abilities

3.4 Methodological Approaches

As mentioned above, various nursing-specific methodological approaches have emerged over the past four decades. These approaches fall into the following categories: 1) Wilson and Wilsonian-derived approaches, 2) Pragmatic utility approaches inspired by Morse, and 3) Evolutionary approaches based on Rodgers (Weaver & Mitcham, 2008). Each category will be briefly presented, followed by a justification for using Rodgers in this study

3.4.1 Wilsonian Approach

The Wilsonian approach was published initially outside of nursing in 1963 and was a framework intended as a tool to teach high school students (Rodgers, 2000). According to Rodgers (2000), this approach was designed to help students work through abstract questions and develop skills to answer conceptual questions. Philosophically, it is aligned with the entity view of concepts and positivism. Its objective is to create something resembling a dictionary definition by conducting an eleven-step linear analysis (Risjord, 2009).

Table 3.2 Wilson's eleven-step approach (Risjord, 2009)

1. Isolating questions of concept
2. Finding right answers
3. Model cases
4. Contrary cases
5. Related cases
6. Borderline cases
7. Invented cases
8. Social context
9. Underlying anxiety
10. Practical results
11. Results in language

Wilson's approach has endured within the nursing discipline as an easy-to-use technique for discerning fundamental features of a concept (Rodgers, 2000). However, while it enhances critical thinking skills, it was not necessarily intended as a framework for producing a scientific examination of a concept (Hupcey & Penrod, 2005). A significant limitation of this approach, for example, is its reliance on ordinary language and common usage of the concept (Risjord, 2009).

3.4.2 Wilsonian-Derived Approaches

There are three main approaches derived from the work of Wilson (1963), which include Walker and Avant (1983), Chinn and Jacobs/Kramer (1983), and Schwartz-Barcott and Kim (1986). These approaches are underpinned by an entity view of concepts and influenced by positivism (Weaver & Mitcham, 2008). They seek to identify the essence of a concept and its core defining features by using linear, step-by-step analysis (Weaver & Mitcham, 2008).

Although each methodological approach aligns with similar philosophical underpinnings, the goals vary slightly based on the selected approach. Walker and Avant (1983) strive to use concept analysis as a strategy for theory construction (Risjord, 2009). As such, the goal of concept analysis is to examine the structure and function of a concept. The analysis aims to define relevant and irrelevant attributes of the concept and determine similarities and differences

between concepts (Weaver & Mitcham, 2008). Chinn and Jacobs/Kramer (1983, 1987, 1991) goal is to create meaning around nursing concepts through reflection (Weaver & Mitcham, 2008). They explore feelings, values, and attitudes associated with phenomena of interest and ultimately provide concrete conceptual meaning (Weaver & Mitcham, 2008). The third variation of Wilson's (1969) method was developed by Schwartz-Barcott and Kim (1986) to both educate graduate-level students and to improve upon Wilson's original methodological approach. This approach explicitly includes both theoretical and empirical activities, which are integrated to ultimately define the concept and evaluate the importance and applicability to nursing (Rodgers, 2000).

The key characteristics of the Wilsonian-derived concept analyses are similar, with minor exceptions. Regardless of the selected approach, each procedure offers a set of steps to be followed (Weaver & Mitcham, 2008). Each approach begins by selecting a concept, determining the purpose or rationale of the inquiry, and identifying how the concept has been used within the literature and other data sources (Weaver & Mitcham, 2008). Schwartz-Barcott and Kim (1986) supplement their data sources with interviews and field observations to determine whether the concept in the literature aligns with practical reality. Data collection and analysis using Wilsonian-derived approaches is iterative (Weaver & Mitcham, 2008). They can also include the construction of cases that illustrate the essence of the concept (Weaver & Mitcham, 2008). The research end product typically includes a definition, as well as conditions required for the concept to occur (antecedents), the outcomes of concept use (results), concrete evidence of the concept in use (empirical evidence), and exemplars that portray the essence of the concept (Weaver & Mitcham, 2008).

Regardless of the selected Wilsonian-derived approach, certain limitations exist. Weaver and Mitcham (2008) note that dictionary definitions and invented cases in the Walker and Avant and Chinn and Jacobs approaches reduce validity and relevance to the discipline of nursing. Furthermore, given the entity view underpinning Wilsonian-derived approaches, the emphasis on consistency of conceptual definitions across contexts reduces the internal consistency and fit with phenomena of interest to nursing (Weaver & Mitcham, 2008). Additionally, rigour is not part of evaluating the methodological processes and products within the Walker and Avant (1983) and Schwartz-Barcott and Kim (1986) approaches.

3.4.3 Pragmatic Utility Approach

Morse (2000) developed the pragmatic utility approach as an alternative to Wilsonian-derived concept analysis approaches. According to Weaver and Mitcham (2008), the philosophical underpinnings of the pragmatic utility approach most closely align with critical theory. Morse (2000) recognizes that concepts represent a probabilistic truth; however, absolute truth may not be attainable. Nevertheless, the pragmatic utility approach is underpinned by an entity view of concepts as they must meet specific stringent criteria, including boundary setting and identifying conceptual adequacy (Weaver & Mitcham, 2008). The purpose of Morse's concept analysis approach is to evaluate concept use by "comparing and contrasting conceptual applications in particular disciplines, determine conceptual adequacy with competing concepts, and identifying gaps, inconsistencies, and boundaries" (Weaver & Mitcham, 2008, p.186).

The key characteristics of the pragmatic utility approach differ from Wilsonian-derived approaches. It has guiding principles as opposed to a series of steps. The guiding principles include: clarifying the purpose of the analysis, selecting literature to ensure validity, identifying critical questions, and synthesizing the results (Morse, 2000). Data sources must be specific to

disciplinary literature to provide disciplinary context. Data sampling, according to Morse (2000), should be inclusive of all literature within the discipline that is relevant to the concept. During analysis, there is an emphasis on evaluating the maturity of a concept by using criteria set out by Morse and colleagues (1996). The pragmatic utility approach is helpful for concepts ranging from immature and partially mature as long as there is sufficient literature for analysis. The product of a concept analysis using the pragmatic utility approach integrates prior research about the concept to guide further research and inform the discipline about the use and relevance of the concept (Weaver & Mitcham, 2008).

The pragmatic utility approach is limited to immature and partially mature concepts, as defined by Morse (2000). However, Morse does not offer guidance on assessing the maturity of a concept. Consequently, researchers have to determine the state of a concept within the nursing discipline and explain why Morse's approach is a good fit based on the concept's maturity. Furthermore, Morse (2000) states that researchers should include all relevant literature in their analysis. Yet, it is important to question whether it is possible to obtain and read all literature surrounding a chosen concept (Weaver & Mitcham, 2008).

3.4.4 Rodger's Evolutionary Approach

Rodger (1989) considered the philosophical foundations of the previous concept analysis approaches and offered an alternative approach that "overcomes difficulties with a positivistic or reductionistic view and addresses contemporary concerns valuing dynamism and interrelationships within reality" (p.332). Rodgers understands concepts from a dispositional view and, as a result, embraces an evolutionary understanding of concepts that sees concepts as continually evolving and subject to change (Rodgers, 2000). The philosophical foundation of the evolutionary approach aligns most closely with the interpretive (constructivist) paradigm,

recognizing that concepts change and are context-dependent (Weaver & Mitcham, 2008). Rodgers and Knafl (2000) explains that there is no endpoint to conceptual evolution unless a concept loses significance to the discipline. Furthermore, she states that attention to context is vital to concept analysis and the nursing discipline more broadly, given that nursing disciplinary work is context-dependent and attentive to person, health, environment, nursing, and, more recently, social justice.

The actual procedure of an evolutionary concept analysis shares similarities with Wilsonian-derived approaches because it also focuses on antecedents, attributes, and consequences. However, it differs from the above approaches in its focus on inquiry and interpretation of results (Rodgers, 2000). Rodger's approach emphasizes the need for an inductive approach and rigorous analysis of the evolution of a concept, as opposed to starting the investigation with preconceived ideas of the concept (Rodgers, 2000). Possible data sources in data collection can include "printed media, such as newspapers or professional literature; interviews or other spoken language; and the performing arts" (Rodgers, 2000, p.84). The analytic procedure will be discussed in more detail below; however, it is important to note that data collection and analysis are done separately, which assists the researcher in avoiding premature conclusions or pointing the analysis toward preconceived notions (Rodgers, 2000). The resultant product of the analysis is not intended to reveal a definition or rigid boundaries regarding what is and is not inclusive of the concept. Instead, the evolutionary approach is consistent with the idea that concepts are continually developing. The concept analysis provides the clarity necessary to create a strong foundation for further inquiry and development (Rodgers, 2000).

Possible limitations exist within the evolutionary approach to concept analysis. According to Weaver and Mitcham (2008), identifying a single model as an exemplar within the procedures is inconsistent with the dispositional view of concepts and the idea that concepts are context-dependent. The adequacy of data may not be reached when literature outside of the analysis has to be used to depict a model case, which Rodgers has previously described as acceptable (Weaver & Mitcham, 2008). Furthermore, Weaver and Mitcham (2008) also note that statistical sampling methods may compromise validity because a statistically representative sample that is randomly selected may not fully characterize the concept.

3.5 An Evolutionary Concept Analysis of Self-Care in Heart Failure

Rodgers' (2000) evolutionary approach is suitable for analyzing the concept of self-care in HF because it is a structured yet flexible process that still allows for an inductive inquiry and emphasizes context and evolution. The process is flexible because the researcher can illuminate how the concept has acquired meaning as nurses working in heart failure have come to use it and apply it to particular situations, contexts, and interventions. Furthermore, Rodgers' approach fits with the research objectives because the purpose of this concept analysis is not to define the concept of self-care in HF. The goal is to explore the evolution of self-care in HF and critically analyze the uptake of this concept and its implications for theory, research, policy, and practice. Self-care has a particular function in the discipline of nursing and the field of HF, one that has changed and developed over time. Given the rise in the use of the concept in recent years, it is essential to reflect on its applications while also uncovering possible consequences that current conceptualizations of self-care have on patients, interventions, and the nursing discipline.

Rodgers' approach aligns with critical theory as this paradigm maintains a position of historical realism (Weaver & Olson, 2006). This paradigm acknowledges that reality is shaped

by historical, social, political, cultural, and economic factors. Such factors produce a "reality," but that reality is a construct that needs to be critically examined and deconstructed. A concept analysis using an evolutionary approach aligns with critical theory because it also emphasizes the contextual and temporal nature of concepts (Rodgers, 2000). Furthermore, it challenges the neutrality of concepts as mere tools or things. From an epistemological position, Rodgers' evolutionary approach also aligns with critical theory because there is an understanding that findings are value-mediated and that the researcher inevitably influences the end product (Guba & Lincoln, 1994).

Finally, Rodgers' approach aligns well with the research goal of uncovering neoliberal ideologies inherent in self-care in HF. According to Rodgers (2000), when people have grasped a concept, they can think, converse, and categorize phenomena or situations. Without possessing or grasping a concept, one cannot accomplish or even become involved in such activities. A critical concept analysis on self-care in HF pushes us to engage more critically and deeply around the neoliberal influences and ideologies that underpinned this concept, which can then open dialogue and debate. This can subsequently influence and guide further research, theory development, policy, and practice, which is the ultimate purpose of this concept analysis. As a nurse working in HF, I see great value in incorporating a critical lens into this concept analysis and working through Rodgers' approach with a clear intention of situating self-care in a broader context.

3.5.1 Process and Application

This section outlines the research process I followed to conduct an evolutionary concept analysis of self-care in heart failure. Rodgers' approach includes six primary activities, which are outlined in table 3.3. These activities were not accomplished linearly as some steps are iterative

throughout the process (Rodgers, 2000). For each activity, I will describe the process (i.e., what Rodgers described in her book), followed by its application (i.e., how I applied Rodgers' approach to my analysis).

Table 3.3 Primary activities of Rodgers' evolutionary approach (Rodgers, 2000).

- Identify the concept of interest and associated expressions (including surrogate terms)
- Identify and select an appropriate realm (setting and sample) for data collection
- Collect data relevant to identify:
  a) Attributes of the concept
  b) The contextual basis of the concept, including interdisciplinary, sociocultural, and temporal variations
- Analyze data regarding the above characteristics of the concept
- Identify an exemplar of the concept, if appropriate
- Identify implications and hypotheses for further development of the concept

3.5.1.1 Identify the Concept of Interest

Process. According to Rodgers (2000), although the evolutionary concept analysis approach is iterative, the first step is always to determine and identify the concept of interest and associated expressions. Consequently, familiarity with the literature is crucial as it enables the researcher to select the concept and distinguish it from associated expressions (Rodgers, 2000). According to Tofthagen and Fagerstrom (2010), several concepts in the literature may express similar ideas and affect the choice of concept to analyze. Therefore, an important first step is to review the literature and document the language used across sources.

Application. Going into the study, I had some familiarity with the concept of self-care in HF. Using this knowledge, I started by creating a concept map (Appendix A) to identify the concept of interest, associated expressions, and possible gaps in knowledge. This concept map was shared with my thesis committee for feedback. With this feedback, I then began a literature review that included self-care, self-management, self-efficacy, and self-monitoring. These associated expressions were initially selected to understand and review the circumstances

whereby they described similar or not so similar phenomena, as well as their use within different disciplinary contexts. After reviewing the literature and developing a better understanding of the historical underpinnings of the various selected expressions, as highlighted in chapter two, I decided to focus solely on self-care. This decision was based on the literature review, which showed a robust uptake and use of the concept in the nursing literature. It was also based on the specific relevance and centrality of self-care in HF. Once the decision was made to focus on the concept of self-care in HF nursing, I moved to the next step of selecting the setting and sample for the concept analysis.

3.5.1.2 Selecting Setting and Sample

Process. This step of the concept analysis requires the researcher to determine the time period for the analysis, the context, the disciplinary focus, and the types of literature to be included or excluded (Rodgers, 2000). Rodgers (2000) recommends that researchers build their sample using systematic stratified sampling. However, in practice, researchers who have published their evolutionary concept analysis have used stratified, random, and purposeful sampling (Weaver & Mitcham, 2008). According to Rodgers (2000), at least thirty items from each stratum or 20% of the total population, whichever is greater, should be selected for the sample. Stratification of selected data can be by discipline, type of literature, or year (Rodgers, 2000). The ultimate goal is to have a comprehensive and proportionate representation of the concept included in the sample.

Application. For this concept analysis, the setting was limited to peer-reviewed nursing literature. Inclusion criteria included: articles published in a nursing journal, articles authored by a nurse researcher, and articles written by an interdisciplinary team or published in an allied health journal with a lead nursing author. Furthermore, because the concept analysis was aimed

at examining the concept of self-care within the context of HF, I limited the sample to this field. Here, it is important to note that there are nuanced meanings associated with self-care depending on the particular field of nursing in which it is used and evolves. For example, self-care in mental health may have a different meaning and may be used differently than HF. For this reason, I only included literature that specifically focused on self-care in the context of HF and, more specifically, the context of HF community or clinic care. Hospital HF care was thus excluded from the sample.

The period included in this study was 2002-2021. Prior to 2002, there was very little academic literature published on self-care in HF community or clinic care. The sample was limited to academic literature to help focus the analysis on a particular evolution, acquisition of meaning, and concept use. The grey literature was beyond the scope of the study, but could offer an interesting opportunity to analyze the concept of self-care in HF in a subsequent study. Articles featuring a research design or a discussion of self-care in HF were included in the final sample. I did not use geographical location as an inclusion or exclusion criterion, but I documented this information during formal analysis and considered it a critical contextual factor for possible variations in concept evolution, use, and meaning. The sample was limited to articles published in English. Finally, I excluded articles focused on children and youth because the boundaries of this concept analysis were only relevant to an adult population. Heart conditions among children and youth can certainly lead to HF, but the implications may differ for adults who acquire HF self-care skills later in life.

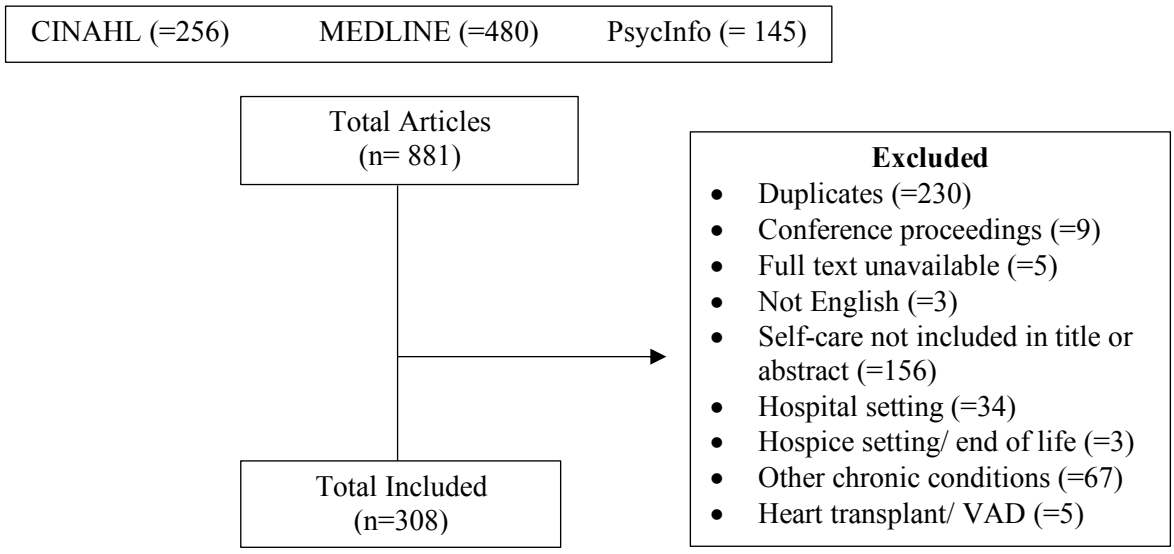
Table 3.4 Inclusion and exclusion criteria

Inclusion	Exclusion
• Nurse as lead author or article published in a nursing journal • Heart failure self-care in title or abstract	• Acute care or hospital settings • Self-care is not present in the title or abstract

• Published between 2002-2021 • Written in English • Complete text available from the database • Adult population • Community and clinic settings	• Multiple chronic conditions • Focus is on self-care with ventricular assist devices or heart transplant • Palliative care or end of life

The search was conducted using three databases at the recommendation of the librarian at the University of Victoria: 1) CINAHL (Cumulative Index to Nursing & Allied Health Literature), 2) MEDLINE (National Library of Medicine), and 3) PsycInfo (American Psychological Association). The search strategy was as follows: Nurs* AND heart failure AND self-care, as per the librarian's recommendation. A total of 881 articles were retrieved (see Figure 3.1). After applying the inclusion and exclusion criteria, 308 articles were left and then included in the sample.

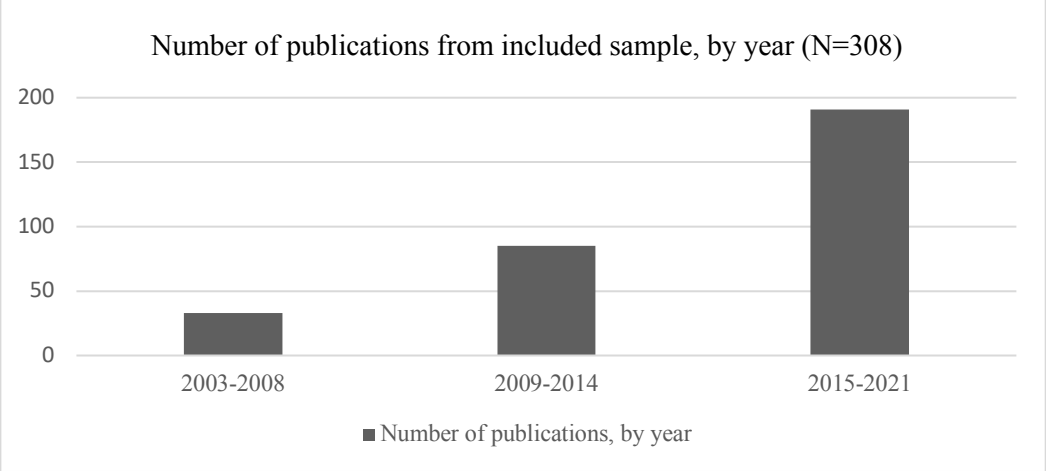
Figure 3.1 Implementation of inclusion and exclusion criteria



Following Rodger's approach, stratified sampling was completed by first grouping the included articles by publication date (see Figure 3.2). 20% of the articles from each stratum were randomly selected using a random number generator: Seven articles were selected from 2003-

2008, 17 articles from 2009-2014, and 38 articles from 2015-2021. The final sample included 62 articles.

Figure 3.2 Number of articles in the sample, organized by year



3.5.1.3 Data Collection and Management

Process. Data collection starts once the sample has been finalized (Rodgers, 2000). The first step in the analysis is to read each article at least once to identify the article's tone and explore the use of the concept (Rodgers, 2000). According to Rodgers (2000), the researcher can use separate sheets of paper to record relevant data to each major category: antecedents, attributes, consequences, etc. Other tools, such as Excel or OneNote, can also be used. Notes and journaling are also part of the process and allow the researcher to document methodological decisions, potential avenues for the analysis, and relevant information such as context, patterns, chronology, and so forth. Every researcher develops an individual data management style; however, according to Rodgers (2000), it is important to stay true to the purpose of evolutionary concept analysis. As such, the data management style should allow the researcher to extract relevant data from the articles, categorize and contextualize the data, and identify new conceptual insights into the evolution, the use, and the meaning of the concept (Rodgers, 2000).

Application. I used Microsoft Excel to collect and manage the sample. Each article was given an identification number and entered into separate rows. Each article was read once to understand the article's tone and explore the general use of the concept. Each article was then read a second time, and the data was extracted into the following columns: year of publication, location, antecedents, attributes, consequences, examples, surrogate expressions, and related terms. Relevant quotes were highlighted and recorded in a separate column. I used another sheet to document and reflect on differences and similarities between stratum (2003-2008, 2009-2014, 2015-2021), as well as differences and similarities between geographical locations. Finally, a fourth sheet was used to collect extra information from research articles to create a database of study participants and their characteristics. I also took notes throughout the process using OneNote. At the beginning of the analysis, I tested my approach by selecting two articles and walking through the steps described above with my thesis supervisor. After a round of feedback, I proceeded with the remaining data collection and analysis.

3.5.1.4 Data Analysis

Process. The analytic approach in evolutionary concept analysis is similar to thematic analysis. Once the data extraction is completed and organized into categories, each category is examined separately to identify major themes (Rodgers, 2000). According to Rodgers (2000), the analysis is a process of organizing and reorganizing similar data until relevant themes (and sub-themes) emerge. The focus of the analysis is primarily on identifying antecedents, attributes, and consequences. Antecedents are "events or phenomena that have previously been related to the concept" (Tofthagen & Fagerstrøm, 2010, p.25). When performing data analysis, the researcher may ask questions to guide the analysis, such as "what has happened previously in relation to the concept?" or "which events have been associated with the concept in the past?" (Tofthagen &

Fagerstrøm, 2010, pp. 24-25). Attributes are the characteristics of the concept and core focus of the analysis (Rodgers, 2000). Helpful questions include, "what are the characteristics of the concept?" (Cowles & Rodgers, 2000, p.107) and "how is the concept described in actual praxis?" (Tofthagen & Fagerstrøm, 2010, p.27). Consequences result from the concept being used in particular situations (Tofthagen & Fagerstrøm, 2010). Questions may include: "what happens after the concept" and "what happens as a result of the concept?" (Tofthagen & Fagerstrøm, 2010, p.24).

Surrogate expressions are different words that express the same ideas or phenomena as the selected concept (Tofthagen & Fagerstrøm, 2010). Related terms have similarities to the selected concept but do not have the same characteristics. Questions for the researcher to ask during this phase of analysis include: "do other words say the same thing as the chosen concept?" (Tofthagen & Fagerstrøm, 2010, p.24). Examples of the concept's use may be extracted from the data during the analysis. Examples can help develop a more comprehensive understanding of the concept: how it is used, when it is used, what it means, who uses it, etc. (Tofthagen & Fagerstrøm, 2010).

After completing the above steps, the researcher continues with an inductive analysis of the data looking for areas of similarities and dissimilarities based on contextual factors, such as time, discipline, geographical location and so forth (Rodgers, 2000). The researcher examines the data for areas of agreement and disagreement over time and across stratum (Rodgers, 2000). During this process, the researcher attempts to uncover patterns that create a more fulsome understanding and contextualization of the concept.

Application. I started the analysis by completing the process described above using the initial 25% (16 of 62 articles) of each stratum (2003-2008, 2009-2014, 2015-2021) and creating a table

with a rough list of all the preliminary codes for each category. Once 25% of the articles were analyzed, I started working with my thesis supervisor to move from a rough list to one that could be used to guide the next step in my analysis. Five new articles were then analyzed using the updated and more comprehensive list of codes. Once I confirmed that the codes were working with the new data, I continued to analyze until I reached 50% (31 of 62) of the total articles. At that point in the analysis, I met with my thesis supervisor to formulate preliminary themes for antecedents, attributes, and consequences. These themes were shared with the thesis committee for further feedback. Based on this feedback, themes were tentatively finalized and tested during the final step in the analysis. The rest of the sample was analyzed, and content was examined for agreement and disagreement with the proposed themes. The notes related to time, context, geographical location, and study participant characteristics were compiled and used to contextualize the findings – and most importantly, to critically interrogate the concept itself.

3.5.1.5 Identifying an Exemplar

Process. According to Rodgers (2000), exemplars can be identified to provide a practical example or demonstrate the concept in a relevant context. The aim of identifying an exemplar is to show the characteristics of a concept in relevant contexts to enhance clarity (Rodgers, 2000). The goal is to find an example that is generic enough to present the concept yet specific enough to illustrate the antecedents, attributes, and consequences. The researcher may find it most appropriate to present more than one exemplar when the analysis reveals considerable variation associated with the context and use of the concept (Rodgers, 2000).

Application. Identifying an exemplar is not required as part of evolutionary concept analysis. In fact, many researchers do not complete this step. I attempted to retrieve one or more exemplars and found no exemplars generic enough to present the concept and specific enough to illustrate

my findings. I opted not to include an exemplar and instead focused on providing a more comprehensive analysis of the underpinnings of self-care in HF using a critical lens. In other words, my intention was not so much to find an exemplar of self-care in HF but rather to uncover what has been driving the use of this concept, how the concept represents particular values and ideals, who it applies to, and why it is used extensively in HF.

3.5.1.6 Interpreting the Results

Process. The final step in Rodgers' approach is the interpretation of the results. The next chapter will include a description and discussion of the results in the form of a research article. Additional remarks on the interpretation of the results will also be provided in the final chapter along with recommendations for practice, theory, research, and education.

CHAPTER 4

RESEARCH FINDINGS

This chapter summarized and discusses the research findings in the format of a peer-reviewed manuscript for Advances in Nursing Science (ANS). The manuscript is formatted according to the ANS guidelines. Additional discussion points and recommendations for research, theory, and practice will be provided in the next chapter.

Manuscript submitted to *Advances in Nursing Science*

Time to revisit heart failure self-care: A concept analysis

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Abstract

Self-care is a central concept in heart failure management and nursing practice. Yet, the uptake of heart failure self-care has been uncritical and detached from broader contexts. Therefore, heart failure self-care was explored using Rodger's evolutionary concept analysis approach to identify antecedents, attributes, and consequences with attention to context, time, application, and meaning. The analysis suggests that heart failure self-care tends to focus on individual behaviours to the detriment of social and structural determinants of health. It also shifts responsibility away from the healthcare system and onto the individual. Moving forward, a more robust conceptualization of heart failure self-care is needed or possibly, the development of a new concept that focuses beyond the *self*.

Keywords

self-care, heart failure, concept analysis, nursing

Introduction

Heart failure is a chronic condition that has become a global health concern, with a prevalence of over 64.3 million adults worldwide.[1] Although historically considered a condition associated with industrialized countries, evidence suggests that heart failure is also on the rise in developing countries.[2] As survival rates from cardiovascular disease continue to improve and populations continue to age, the prevalence of heart failure will continue to increase over time, along with the need for heart failure care.[3] Given the rising prevalence of heart failure, significant emphasis has been placed on early recognition, treatment, and management within community settings and more specifically, heart failure clinics. The American College of Cardiology Foundation/American Heart Association,[4] The European Society of Cardiology,[5] and The Canadian Cardiovascular Society treatment guidelines[6] recommend heart failure management to improve survival and reduce morbidity, hospitalizations, and symptoms while improving functional capacity and quality of life. Heart failure management typically includes interdisciplinary teams of physicians and nurses to optimize medical, device, and surgical treatment, and to provide self-care support. Self-care, which is primarily within the realm of nursing care, is considered one of the most fundamental elements of heart failure management.[7]

Self-care is a central concept in heart failure management and a large focus of nursing practice.[7-8] Yet, there is a wide range of conceptual understandings and definitions of self-care in the nursing literature. In fact, a content analysis by Godfrey and colleagues found 139 definitions of the concept of self-care in the nursing literature published between 1970 and 2010.[9] In the field of heart failure, self-care is often narrowly defined despite encompassing a complex range of behaviours and processes that are influenced by intersecting individual, relational, environmental, sociocultural, and economic factors.[10] To create further confusion, heart failure

self-care is often used interchangeably with self-management, self-monitoring, self-maintenance, and self-help.[11] As such, conceptual muddiness remains despite heart failure nurses using the concept extensively and nursing having established a strong foundation to theorize and study self-care since the 1950s.

Moreover, the uptake of heart failure self-care has also been somewhat uncritical and detached from the broader social, political, economic, and ideological context in which it is located. This is an important gap that needs to be addressed because the concept of self-care is not neutral; it does reflect specific values, priorities, goals, and orientations. How are heart failure nurses using the concept of self-care? In which situations and for what purposes? What meaning does this concept carry and how does it shape nursing practice as well as nursing theory and research? These questions are the starting point of this paper, which presents and discusses the findings of an evolutionary concept analysis of self-care in the heart failure nursing literature. This type of analysis, at this particular point in time, is important because of rising pressures to adopt micro-level solutions to macro-level problems in health care. Beyond the need for conceptual clarity, which is important for the advancement of nursing knowledge, we see tremendous value in exploring and analyzing this concept because it shapes discourses and practices in heart failure. It also shapes the role of nurses who are largely responsible for communicating self-care expectations to heart failure patients (and their caregivers), monitoring adherence to and effectiveness of self-care interventions, and identifying the factors that influence self-care. It is our hope that this paper can create space for thinking critically about self-care in heart failure and offer new insights into the evolution, use, and meaning of this concept.

Methods

We used Rodgers' evolutionary approach to concept analysis (see Table 1) because it provides a structured yet flexible process that allows researcher to engage in inductive inquiry and pay close attention to context, time, application, and meaning. Rodgers sees concepts as continually evolving and subject to change.[12] As such, her approach does not seek to produce a definition of the concept, but rather to explore the evolution of the concept while also identifying its antecedents, attributes, and consequences. We followed the steps outlined by Rodger's starting with the identification of the concept of interest and associated expressions, followed by the selection of an appropriate setting and sample for data collection.[12]

The setting was limited to the nursing literature. Inclusion criteria included: articles published in a nursing journal, articles authored by a nurse researcher, and articles written by an interdisciplinary team or published in an allied health journal with a lead nursing author. Furthermore, because the concept analysis was aimed at examining the concept of self-care within the context of heart failure, we limited the sample to heart failure and, more specifically, the literature on adult heart failure in community or clinic care. Heart conditions among children and youth can certainly lead to heart failure, but the self-care implications differ for adults who acquire heart failure later in life. The time period included in this study was 2002-2021. Prior to 2002, there was very little academic literature published on self-care in heart failure community or clinic care. The sample was limited to academic literature (e.g., primary studies, systematic reviews, conceptual work) to help focus the analysis on a particular evolution, acquisition of meaning, and concept use. The grey literature was beyond the scope of the study, but could offer an interesting opportunity to analyze the concept of self-care in heart failure in a subsequent study. Articles featuring a research design or a discussion of self-care in heart failure were

included in the final sample. We did not use geographical location as an inclusion or exclusion criterion, but we documented this information during formal analysis and considered it a critical contextual factor for possible variations in concept evolution, use, and meaning. The sample was limited to articles published in English.

The search was conducted using three databases at the recommendation of a specialized librarian: 1) CINAHL (Cumulative Index to Nursing & Allied Health Literature), 2) MEDLINE (National Library of Medicine), and 3) PsycInfo (American Psychological Association). The search strategy was as follows: Nurs* AND heart failure AND self-care, as per the librarian's recommendation. A total of 881 articles were retrieved (see Figure 1). After applying the inclusion and exclusion criteria, 308 articles were left and included in the sample. Following Rodger's approach, stratified sampling was completed by first grouping the included articles by publication date (see Figure 2). 20% of the articles from each stratum were randomly selected using a random number generator: Seven articles were selected from 2003-2008, 17 articles from 2009-2014, and 38 articles from 2015-2021. The final sample included 62 articles.

The analytic process followed the basic structure of Rodgers' approach. Each article was read once to understand the tone and explore the general use of the concept. Each article was then read a second time, and analyzed using the questions outlined by Tofthagen & Fagerstrøm,[13] including: "What has happened previously in relation to the concept? Which events have been associated with the concept in the past? What are the characteristics of the concept? What happens as a result of the concept?".(pp 24,25) Data was extracted into an Excel spreadsheet using the following columns: year of publication, location, antecedents, attributes, consequences, examples of self-care, and related terms and expressions. Relevant quotes were highlighted and recorded in a separate column. We used another sheet to document and reflect on differences and

similarities between stratum (2003-2008, 2009-2014, 2015-2021), as well as differences and similarities between geographical locations. Finally, a fourth sheet was used to collect extra information from research articles to create a database of study participants and their characteristics. 55 of the 62 selected articles included study participants and the aggregated reported characteristics are presented in Table 2.

To ensure rigor, we analyzed the sample in three steps. For the first step, we completed the process described above using the initial 25% (16 of 62 articles) of each stratum (2003-2008, 2009-2014, 2015-2021) and creating a table with a rough list of all the preliminary codes for antecedents, attributes, consequences. Once 25% of the articles were analyzed, we moved from a rough list to one that could be used to guide the second step. Five new articles were then analyzed using the updated and more comprehensive list of codes. Once these codes were saturated, we continued to analyze until we reached 50% (31 of 62) of the total articles. After reaching this point of saturation, we grouped the codes into categories and used the categories to analyze the rest of the sample. Following these steps allowed us to structure the inductive dimension of the analysis, which is essential to the identification of antecedents, attributes, and consequences.

Results

The results of our concept analysis will be organized in three categories, which is consistent with Rodgers' approach. It is important to note that findings related to evolution and context are threaded across all three categories - and throughout the discussion. From a language perspective, the following results use to the term provider, rather than nurse, because this was the terminology primarily used within the sample. For parsimony, we made an effort to limit the

number of references cited. A full list of articles included in our sample is available in Supplementary document (Appendix B in the thesis).

Antecedents

Four categories of antecedents were identified during the analysis, which included 1) person; 2) partner; 3) provider; and 4) system. As shown in Figure 3, we identified some overlap between the antecedents of person and partner, as well as between partner and provider.

There was a prevailing consensus that self-care is preceded by several factors related to the person living with heart failure. In other words, who that person is and what they can draw from to put self-care into practice. Unsurprisingly, emphasis was often placed on personal characteristics, such as age, gender, race, sociodemographic level, and geographical location.[14-21] However, it was not always clear how and which personal characteristics act as precursors of self-care. Symptom profile was also commonly cited as a person-specific factor. Severe symptoms were considered to limit the ability to engage in self-care.[15,19,22-24] In contrast, people who experienced milder symptoms were considered to be more likely engage in self-care.[25] Self-concept was another factor mentioned and included perception of health and control over the situation, previous experiences, and personal beliefs – all of which were believed to influence how confident and motivated someone is to engage in self-care.[16,26-30] Finally, responsibility was identified as a recurrent antecedent of self-care whereby taking responsibility was seen as a precursor of self-care.[15,16,31-34] Overall, there was a strong emphasis on the idea that self-care starts *within* the person and is preceded by personal factors such as personal characteristics, milder symptoms, a strong self-concept, and commitment to take responsibility for one's health.

Some antecedents overlapped between the person and the partner (i.e. the caregiver spouse, child, relative, or friend.), most notably knowledge related to heart failure. Both the

person with heart failure and their care partner were expected to gain the necessary knowledge and understanding of heart failure management to perform self-care successfully.[14,24,34,35-38] Health literacy was considered an essential precursor to gaining this knowledge and understanding. In fact, low health literacy levels were consistently identified as a barrier to effective self-care.[26,39-40] The acquisition of self-care skills was also mentioned in the literature, but how they were acquired was not made explicit.[22,35] A second overlapping antecedent was the health status (mental and physical) of the person and their care partner, which were considered to influence self-care. This was evident by literature detailing how poor health status negatively impacts self-care. For example, cognitive deficits and co-morbidities were often mentioned as common factors that create difficulties the person performing self-care and the care partner supporting self-care.[16,19,20,24,38,41,42] Furthermore, there was a consensus in the literature that mental health plays an important role in performing and supporting self-care.[19] Feeling depressed and being anxious were the two most commonly mentioned obstacles to effective self-care.[19] To sum up, self-care requires that both the person and their care partner be knowledgeable and have the cognitive, mental, and physical capacity to put their knowledge into practice.

We also found overlapping antecedents between the partner and the provider, including the nature of the relationship and the support offered.[42] From the partner perspective, the nature of the relationship (e.g., spouse, friend, etc.) was a key determinant of the support provided and its impact on self-care.[43,44] From the provider's perspective, a trusting relationship was considered the most conducive to self-care,[27,34] whereas paternalistic relationships were not.[19] Supporting the patient was considered essential from both the partner and provider. Partner support emphasized co-management and active involvement in self-care activities when the person requires assistance.[43-45] Provider support emphasized implementing individualized

strategies, such as counselling and motivational interviewing, and fostering effective self-care practices.[23,46,47] Provider-specific antecedents included patient education to increase self-care knowledge, understanding, and skills,[40,44,45,48] as well as provider experience.[21,48] In summary, the partner and provider antecedents suggest that self-care is more relational than the literature suggests and that support from others needs to be in place for self-care to be fully realized.

System-level antecedents influence self-care; yet, they were seldomly mentioned in our sample. From what we gathered, the type of self-care intervention, including location, intensity, and duration of the intervention, as well as the team of providers who deliver the interventions preceded self-care.[32,33,48,49] Access to technology as a means of monitoring self-care activities and outcomes, and reducing costs associated with heart failure management was also mentioned .[34,37,49] Finally, resources allocated to self-care interventions can also make a difference in self-care uptake outcomes.[50] Overall, our analysis suggests that antecedents tend to focus heavily on person- and partner-specific characteristics as instrumental in shaping their ability to perform and support self-care. Relational antecedents of self-care are not as developed, but they suggest that partner and provider dyads are crucial to self-care. Finally, system-level antecedents remain largely overlooked and point to important gaps in our understanding of self-care in heart failure.

Attributes

We identified five main attributes during the analysis. We found self-care to be:

1) a set of behaviours that are universally applied and measurable;
2) an active and demanding daily process;
3) an experience that ranges from autonomous to assisted care;
4) a standard that requires compliance and monitoring; and
5) a strategy to cut healthcare costs and utilization.

A set of behaviours that are universally applied and measurable

The most salient attribute of self-care emerged from the broad and consistent use of the concept to designate a particular set of fundamental behaviours. They include: weighing oneself daily, following sodium and fluid restriction recommendations, avoiding alcohol, smoking cessation, exercising, taking medication as prescribed, maintaining updated vaccinations, balancing activity with rest, weight control if applicable, symptom monitoring, and seeking professional advice when symptom changes occur. There was consensus within the literature that these behaviours, known as heart failure self-care behaviours, are essential to maintain clinical stability, manage or prevent problematic symptoms, improve quality of life, prevent hospitalization, and decrease morbidity and mortality.[32,51,52] In other words, once a diagnosis of heart failure is made, these behaviours are considered necessary to feel better, live longer, and reduce the impact of heart failure on system resources. Furthermore, these behaviours are universal in that they are applied to all heart failure patients regardless of geographical location, culture, language, and so forth.[25,38,49] Our sample included studies from 18 countries spreading across all five continents, yet we found the same set of universal self-care behaviours cited and recommended throughout.[37,53] Moreover, when we analyzed the sample for similarities and differences over time, we saw no change in the use of the concept to designate this set of behaviours.[14,15,54,55] One salient feature of the self-care behaviours was the underlying goal of measuring and monitoring them. In other words, the concept of self-care was used to refer to these behaviours, but it also carried the particular meaning that such behaviours are "standard" in heart failure care and objectively measurable.

An active and demanding daily process

The concept of self-care was also used to describe *how* people living with heart failure put self-care behaviours into practice on a day-to-day basis. There was an overarching emphasis on active participation in the self-care process.[15,55] This process was predominantly described as active, deliberate, cognitive in nature, and requiring ongoing decision-making.[15,16,38,56] For example, Vellone and colleagues[45] noted that while engaging in passive behaviours is possible, such as following treatment advice, self-care is predominantly an active process that requires ongoing actions and decisions. It is also a daily process that unfolds in real-world situations and requires the person to assess, adjust, evaluate, etc.[14,38] There was an acknowledgement in the literature that self-care *as a process* of making decisions and integrating self-care behaviours into daily life was complex, unrelenting, and burdensome.[19,44] Du and colleagues[57] also pointed out that sustaining this process over time was complex and particularly challenging. Furthermore, Moser and Watkins[19] noted that this process becomes increasingly more complex and time-consuming as heart failure progresses. As they point out, "it is precisely when people could benefit from self-care the most that self-care efforts may fail".(p 206) It became clear during our analysis that although the concept of self-care is commonly used to describe a set of universal and measurable behaviours, the process of *doing self-care* is active, demanding, arduous, time-consuming, and progressively more complex over time, thus requiring increasing support and assistance. Circling back to the antecedents, this further illustrates why person-specific antecedents are largely inadequate as precursors of self-care as a process.

An experience that ranges from autonomous to assisted care

Throughout our analysis, there was a persistent tension between the autonomous conceptualization of self-care and the reality that many people living with heart failure often

require assistance to gain knowledge, make decisions, and perform self-care. Studies repeatedly emphasized the individual nature of self-care and the simultaneous need to engage with healthcare providers and social support systems to engage in self-care effectively.[14,15,23,50] The earlier literature in our sample primarily located self-care behaviours and self-care processes within the realm of the individual, emphasizing both individual choice and responsibility.[16,18,32,43] As such, there was a general assumption that while self-care is both desirable and effective, it was ultimately up to the person living with heart failure to make a choice and take responsibility for their health. Our analysis revealed that heart failure self-care is autonomous until the late 2000s, when scholars started conceptualizing self-care as a shared experience. Heart failure self-care was thus expanded upon to include care partners and their role in supporting heart failure self-care.[42,44,58] After that, we noted an increased mention of caregiver contributions to symptom assessment and management[59] and emotional and psychosocial support,[58] for example. There was also increased recognition that caregiver contributions tend to increase as heart failure progresses and capacity for autonomous self-care is lost.[43] Interestingly, we found a conceptual tension at the heart of the concept of self-care because, at its core, it is centred on the care of the *self*. It begs the question of whether "assisted" self-care remains within the realm of the concept of self-care or if it falls within the concept of caregiving. Furthermore, the differentiation between *assisting with* self-care and *doing* the self-care *for* remained unclear.

A standard that requires compliance and monitoring

Embedded in the concept of heart failure self-care is the need for compliance and monitoring. This stems from the fact that self-care is primarily understood as a set of standard and measurable behaviours that have to be performed every day by the person living with heart failure. In that sense, self-care is quite prescriptive. It sets specific goals that have to be met to

generate the pre-specified desired outcomes associated with self-care, such as symptom monitoring and management, treatment adherence, and mastering heart failure related knowledge.[52,60,61] These goals are not aspirational, and it is for this reason that compliance and monitoring are required. In our analysis, we found that the role of healthcare providers was consistently discussed as a means of assessing and improving self-care compliance.[14,16,30,46] Furthermore, we noted an increasing trend over time toward using technology to monitor compliance, create new opportunities for ongoing (remote) monitoring, and ensure continuity of provider interventions from the clinic setting into the home.[62] Finally, we identified an inextricable link between expectations of compliance (confirmed with monitoring) and the pejorative labelling of those who were unwilling or unable to achieve the self-care metrics. People who were unable to achieve self-care metrics were described as having poor, ineffective, inadequate, unsuccessful, non-adherent, non-compliant, and failed self-care.[19,21,22,52] However, it is worth pointing out that qualitative studies included in our sample suggested that patient perception and self-report of self-care were often at odds with the assessment of providers.[50,54] This is an important finding because it raises questions about the concept of self-care. Our analysis shows that antecedents and attributes tend to focus almost exclusively on the *self* in self-care. Yet, when it comes to compliance and monitoring, the self disappears and is replaced by the external (and increasingly technological) gaze of providers.

A strategy to cut healthcare costs and utilization

The concept of heart failure self-care is underpinned by the need to reduce healthcare costs and utilization. When scholars used this concept, they did so to convey the importance of preventing costly complications and decompensations from heart failure. For example, in their article Chen and colleagues[59] stated that total direct medical costs for heart failure in the United States was

estimated to be $21 billion dollars annually and expected to increase to $53 billion by 2030. Deek and colleagues[63] noted that a single heart failure hospitalization exceeds $4000 US dollars in Lebanon, and costs the country over $1 million US dollars annually. Son[64] indicated that heart failure management costs up to 2% of all healthcare expenditures in South Korea. This attribute was so pervasive that 90% of the articles (56/62) included in our sample explicitly stated that the purpose of self-care was to reduce emergency department visits and hospitalizations. Moreover, it was noted throughout the sample that the majority of heart failure-related hospitalizations could be traced back to *failed self-care.*[19,35,38,59] Some studies furthered this idea by noting that heart failure was a societal burden and that failure to engage in effective self-care negatively impacted the broader economy through loss of work productivity, for example.[30,55,56,63] Along the same lines, assisted self-care was seen to cut healthcare costs and utilization.[45] To conclude this section on attributes, it is evident that heart failure self-care has acquired multiple layers of meanings through use and evolution. To fully appreciate these meanings, which we have summarized in the aforementioned attributes, the cost-cutting imperative that underpins self-care must be made explicit. Only then is it possible to contextualize the standardization of self-care, the role of compliance and monitoring in the care of people with heart failure, and the overwhelming focus on placing the responsibility onto the person (and by extension onto caregivers) – and less so on the challenging nature of self-care as a process. As we turn to the consequences, it is essential to keep this in mind since the consequences discussed in our sample tend to reflect the former, not the latter.

Consequences

We identified two types of consequences: objective outcomes (i.e., observer reported) and subjective (i.e., patient reported) outcomes. System-level outcomes were not mentioned in the

sample. Objective outcomes included biomedical measurements used to determine self-care uptake and effectiveness. These measurements were also used to predict anticipated improvements in heart failure as a result of self-care (i.e., successful self-care should result in). The most common objective outcomes were based on 24-hour urine sodium tests to monitor adherence to sodium restrictions, lower myocardial stress through serum brain-natriuretic peptides tests, and improved ejection fraction measurements.[25,28,32,49,53] Other objective outcomes were mentioned, such as improved symptom management and better uptake of self-care behaviours, both of which are measured using the Self-care of Heart Failure Index (SCHFI).[46,63,65] Quality of life was typically assessed using self-rating scales and included items such as appetite, sleep, physical activity, stress, and overall wellbeing.[40,46,65] Self-efficacy was also frequently measured using the SCHFI.[25,38,40] Finally, decreased mortality was persistently cited as an objective outcome resulting from effective heart failure self-care.[28,44,45]

Consequences for heart failure self-care were overwhelmingly objective in nature and quantitatively studied. None of the selected article in our sample described what the consequences of self-care were from the perspective of people living with heart failure (and their care partners). The few subjective consequences found in the sample included perceived improvements in quality of life, physical functioning, social functioning, and emotional and mental wellbeing.[14,40,44,46,47] Emotional and mental wellbeing included feeling safer, reduced feelings of hopelessness, and greater acceptance of their condition.[34] Improvement in family dynamics were also reported because self-care, when effectively performed, was associated with decreased caregiver irritation, fatigue, and frustration.[22] However, it is important to point out that self-care can create conflict, especially when self-care behaviours did not seem important or

diverged from personal beliefs.[50] Overall, we found subjective consequences of self-care to be underdeveloped compared to objective consequences.

Discussion

The purpose of this concept analysis was to examine the literature on heart failure self-care and to identify the antecedents, attributes, and consequences of the concept while paying close attention to evolution, context, and use. The antecedents of heart failure focused primarily on the person living with heart failure and their care partner. We found some acknowledgement of relational and system-level antecedents. However, it was evident that the conceptual starting point for thinking about self-care was located within the person living with heart failure. We identified five main attributes of heart failure self-care, which speaks to the many layers of meanings embedded in this concept. We found that authors use heart failure self-care to refer to a core set of universal and measurable behaviours that are undertaken through an active and demanding daily process. This process continues to be predominantly seen as an autonomous process despite some recognition that it can and often does require assistance. Furthermore, we noted that heart failure self-care came with an expectation of compliance and monitoring and was underpinned by an imperative to cut healthcare costs and utilization. Finally, we identified the consequences of self-care, which included mainly objective outcomes and some references to subjective outcomes. In light of our analysis, we found four pressing conceptual problems within the concept of self-care that require increased attention within the nursing discipline. These include conceptual issues related to evolution, context, meaning, and neoliberal underpinnings.

First, our analysis revealed that the concept of heart failure self-care continues to be primarily conceptualized through an individualistic lens despite decades of knowledge development in nursing showing the importance of adopting approaches that understand health

and illness *in context* (e.g., social and structural determinants of health, health inequities, etc.). We posit that heart failure self-care remains closely tied to Dorothea Orem's conceptualization of self-care[66,67] and assumptions such as the universal nature of self-care needs, the need to increase capacity and responsibility for self-care, and the highly individualistic view of self-care activities.[8,68] In other words, it is as if heart failure self-care is cemented in ways of conceptualizing that, while helpful in the early days of nursing theories, fail to capture the evolution of nursing knowledge and the body of research on the complexity of chronic illness "management". Despite an increased attention and theorizing around heart failure self-care in recent years, the underpinnings of earlier self-care theories remain unchanged.[66,67] As such, the concept itself fails to illustrate *how* people living with heart failure are impacted by social and structural determinants of health, for example, and *to what extent* they can truly engage in the prescribed self-care behaviours. The fact that social determinants of health are entirely absent from antecedents speaks volumes about the limited evolution of the concept. In turn, it raises important questions about the implications of using the concept in practice. While some may argue that the inclusion of care partners constitutes a form of evolution, we disagree primarily because the care partners are seen as extensions of the *self* (i.e., they are doing what the person is unable to do). What is lacking from the literature is a more complex understanding of the relational dimensions of self-care, and as pointed out above, a nuanced distinction of 'assisted self-care' and 'caregiving'.

Second, despite the diversity of our sample (e.g. geography, time period, etc.), we did not see this diversity reflected in the use or application of the concept of heart failure self-care. In other words, the concept itself is itself standardized through use and application. Over time, it has not acquired new meanings despite being used across various countries, cultures, and

worldviews, nor has its meanings been challenged over the years. We found it interesting that personal beliefs, attitudes, and perceptions were frequently acknowledged within the sample as antecedents to heart failure self-care, yet the concept itself was never discussed as a potential barrier or limit. Santos Salas[69] points out in her critique of American nursing theories and their exportation to the rest of the world that many central concepts in nursing generate problems in practice because they are unsuitable for various reasons, including language, culture, worldview, and so forth. For example, Orem's concept of agency "—often translated as *agencia*—is difficult to understand in Spanish as this term has a completely different usage and meaning in the Spanish language".(p 21) As such, our analysis points to the importance of locating the concept of heart failure self-care and its origins within Western ideologies, critically analyzing its exportation and uptake, and the role self-care plays in colonizing conceptualizations of health and illness in heart failure. Furthermore, it raises pressing questions about the role of self-care in erasing the root causes of inequities in the context of heart failure. As McGibbon and colleagues[70] explain, "nursing's positivist, individualistic and Eurocentric foundations seriously hamper the growth of the profession and nurses' professional capacity to collectively confront the root causes of health inequities".(p 188) For this reason, we are concerned that centering heart failure nursing care on the concept of self-care creates a situation in which little can be done to actually improve health and wellbeing.

Third, we wanted to draw attention to potentially harmful and counterproductive meanings embedded in heart failure self-care. Our analysis shows that living with heart failure is particularly complex and demanding, and as we argued above, this experience is compounded by a range of factors outside the realm of the person with heart failure. However, self-care draws and keeps the focus on the person as the primary site of intervention. For those who succeed at

heart failure self-care, this may not create any issues. For those who face significant barriers or may not want to engage in self-care, this may result in new forms of subjectivities and experiences. As such, we believe that nurses should pay closer attention to the use of self-care in labelling and categorizing patients into groups based on compliance, for example. The binary of compliance and non-compliance exists because heart failure self-care is inherently prescriptive and objectively measurable. It also exists because heart failure self-care is located *within* the person – i.e., their knowledge, their attitudes, their motivation, their responsibility, and so on. However, this binary draws an incomplete portrait of how challenging living with heart failure truly is and why so many struggle with the demands of self-care. If we are to continue using the concept of heart failure self-care in nursing, we believe that additional conceptual and empirical work informed by constructivist and critical approaches is urgently required. More specifically, we believe that a poststructuralist critique of the concept would be helpful in recognizing the power of language and discourse.[71]

Finally, our analysis reveals that the concept of heart failure self-care is underpinned by neoliberal ideals, which shift the burden of responsibility to the individual and links health outcomes with economic interests.[72] Across our sample, people living with heart failure were unequivocally demarcated by their costly burden on healthcare systems and societies. This is an important finding and one that warrants further analysis because of how much emphasis is placed on self-care in heart failure nursing practice and the role nurses play in upholding self-care goals. If self-care is an economic intervention, then what are the implications for nurses and their practice? Our findings suggest that saving healthcare costs and utilization are *not* consequences of self-care. In fact, questions have been raised about the savings generated by self-care.[73] Moreover, our findings suggest that high health care costs and utilization are *not* antecedents of

self-care. In fact, research shows social and structural determinants are the main drivers of costs and utilization in the context of chronic illnesses.[74] Recognizing that neoliberal underpinnings constitute an attribute of heart failure self-care is critical to understand why it risks perpetuating health inequities and offloading the responsibility away from the collective and onto people living with heart failure.[75] As Browne[76] points out, "Nursing knowledge situated within these individualistic frameworks therefore perpetuates a view of individuals as responsible for their own health and health-care, despite persistent social and economic inequities, which are known to heavily influence health and health-care".(p 124)

Conclusion

Our concept analysis suggests that heart failure self-care (as a concept) tends to focus on individual behaviours to the detriment of social and structural determinants of health. It also shifts responsibility for the care and outcomes away from the health care system and onto the individual. We also found that self-care interventions have historically been used to manage costly chronic conditions and ultimately, to limit healthcare expenditures.[75,77] By implementing these interventions, nurses may be unintentionally delivering systemic cost-saving interventions that may not be tailored to the patient rather than attending to system-level determinants of self-care and working from the patient-centered health goals.[77] For all the reasons mentioned above, nurses must engage more critically and deeply with the concept of self-care.

Our concept analysis had some minor limitations. First, our findings reflect the data extracted and analyzed from a selected sample. That sample was limited to 62 articles spreading over three time periods. By statistically sampling 20% of the literature from each stratum, we may have lost important articles that could have shed new light onto the concept of heart failure self-care. However, we achieved high levels of saturation throughout our findings which

suggests that many similarities exist across the body of literature on heart failure self-care. Second, our analysis reflects an iterative and interpretative approach which is consistent with Rodgers' evolutionary concept analysis. Therefore, the goal of our analysis was not to produce a definition or to systematically review of the literature. As such, our findings should be understood as a product of analysis, conducted for the purpose of exploring the use, application, evolution of the concept.

To conclude, this concept analysis comes at an interesting time in nursing as more questions are raised about knowledge production, colonization, and the centering of nursing theories on Western and Eurocentric ideologies. As far back as 1996, nursing scholars were questioning the use of Orem's theory and derived concepts including self-care.[78] While our analysis was not focused on culture per se, it revealed that individualism and neoliberalism are at the heart of heart failure self-care. It also raised important questions about the implicit goals of self-care and how much emphasis is placed on the person at the detriment of social and structural determinants of health. We believe that our paper can pave the way forward for a more robust conceptualization of heart failure self-care or possibly, to push for the development of a new concept that reflects the current state of knowledge and focuses beyond the *self*.

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Table 1 Primary activities of Rodgers' evolutionary approach (Rodgers, 2000).

- Identify the concept of interest and associated expressions (including surrogate terms)
- Identify and select an appropriate realm (setting and sample) for data collection
- Collect data relevant to identify:
  c) Attributes of the concept
  d) The contextual basis of the concept, including interdisciplinary, sociocultural, and temporal variations
- Analyze data regarding the above characteristics of the concept
- Identify an exemplar of the concept, if appropriate
- Identify implications and hypotheses for further development of the concept

Table 2. Reported personal characteristics from the sample (n= 55 of 62 articles)

Number of participants	10,092
Sex	Male: 58% Female: 42%
Average age	65.6 years
Average years living with heart failure	4.4 years
Race	White: 52.1% Asian: 27.9% Black: 16.2% Non-white (not specified): 2.6% Hispanic: 1% Aboriginal: 0.2%
Education	No education: 1.9% High school education or less: 72.7% Greater than high school education: 25.4%
Disease severity	NYHA I: 9.5% NYHA II: 38.3% NYHA III: 40.2% NYHA IV: 12%
Employment status	Employed: 32.5% Unemployed: 33% Retired: 34.5%
Comorbidities	No comorbidities: 26.6% 1 comorbidity: 22.7% 2 comorbidities: 23.4% 3 or more comorbidities: 27.3%

Figure 1. Implementation of inclusion and exclusion criteria

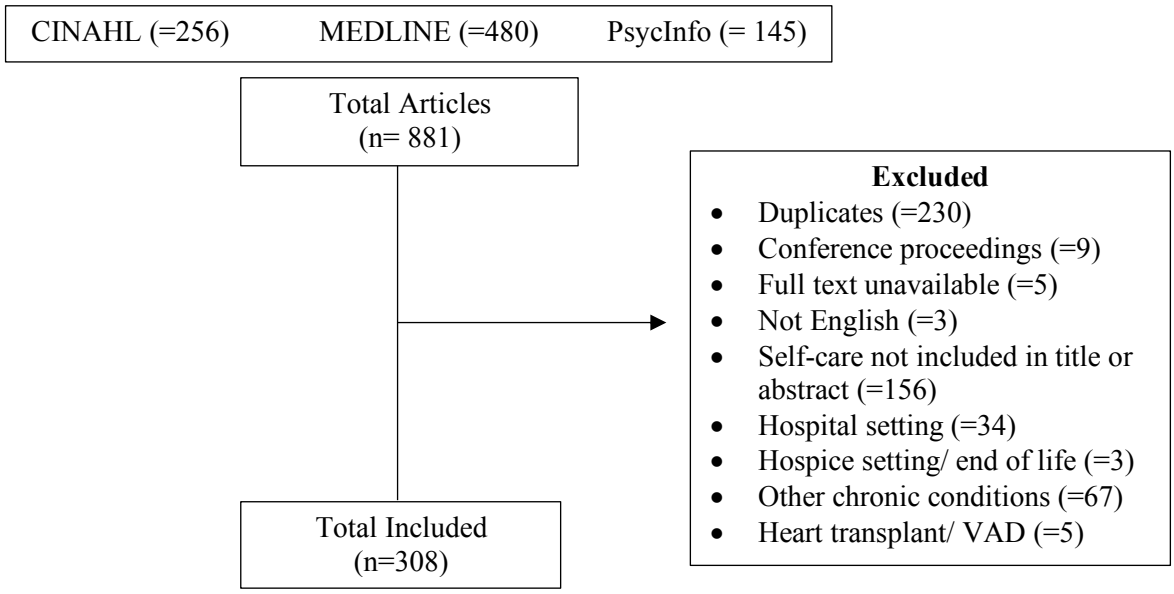


Figure 2. Number of articles in the sample, organized by year

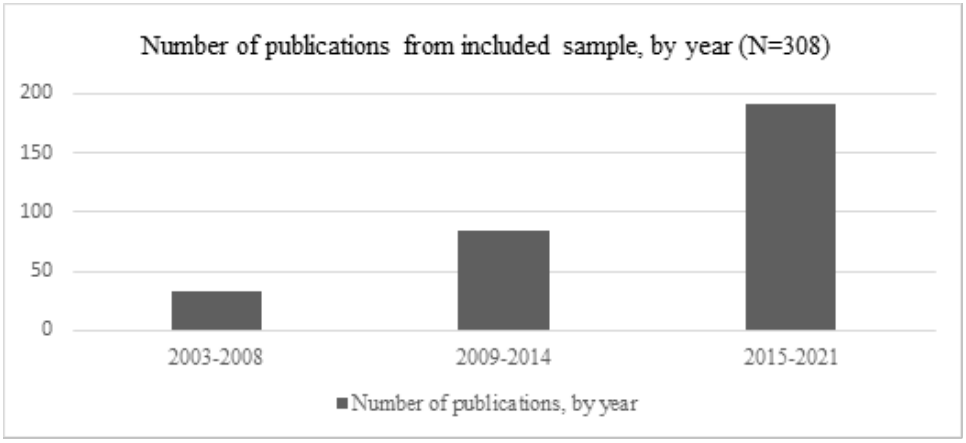
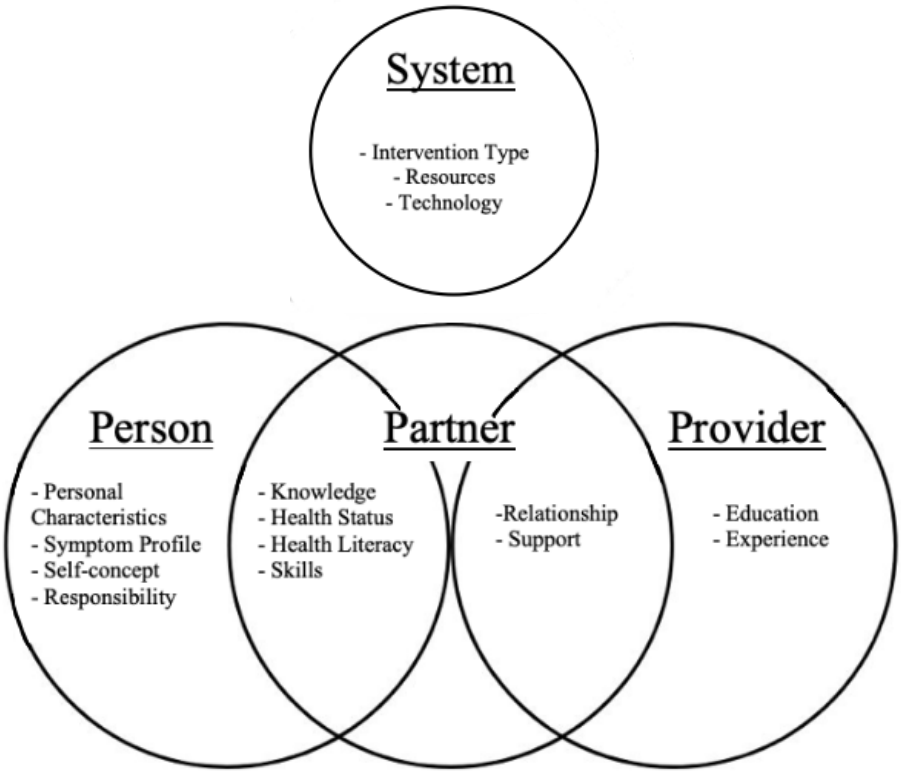


Figure 3. Antecedents of heart failure self-care



CHAPTER 5

RECOMMENDATIONS AND CONCLUSION

This chapter builds on the discussion presented in Chapter 4 and offers a brief overview of recommendations for nursing. For ease of reading, I will follow the same structure as Chapter 2, starting with recommendations for theory, followed by research, and ending with practice. Although many recommendations could be made based on the concept analysis, I have highlighted the most salient ones based on their relevance and importance for the nursing discipline.

5.1 Recommendations for Theory

HF continues to be a significant health concern and undoubtedly requires treatment and management to maintain health and delay disease progression (Ezekowitz et al., 2017). However, HF self-care, in its current conceptual form, has important gaps that contribute to its theoretical shortcomings, and this remains true despite the emergence of new HF-specific nursing theories. As such, I believe it is vital to push for the development of a better-rounded concept to describe the day-to-day experience of living with and "managing" HF with increased attention to the implications of existing conceptual shortcomings on nursing care. In this section, I highlight pressing issues with existing theories, as well as recommend future theoretical development to support nursing research and practice.

If, as suggested by Riegel and colleagues (2016), the influences on HF self-care continue to be theorized as an interaction between the person, the problem, and the environment, then increased attention needs to be placed on the concept of environment. The definition used by Riegel and colleagues (2016) limits the environment to the immediate surroundings and relationships that impact the person with HF. Challenging this definition and pushing its

boundaries is important because the micro-range (or situation-specific) theory of HF self-care was the most cited in our sample (Riegel et al., 2016). Furthermore, the findings of the concept analysis suggest that there is a complex interplay of person, partner, and provider characteristics that are also shaped by system-level factors – the majority of which are not elicited nor discussed in the literature. I contend that reducing the concept of environment to the immediate context in which the person living with HF is located is incomplete and hinders our understanding of self-care. While Attallah and colleagues (2021) have developed a middle-range theory of heart failure self-care that has further theorized the influences of personal, sociocultural, and healthcare factors on self-care, they have not provided much conceptual detail or nuance at this time. Therefore, significant work needs to be done in order to incorporate social and structural determinants of health into the understanding of heart failure – and self-care. For example, 67.5% of the articles including sociodemographic data in our sample reported that patients were not working and 74.6% had a high school education or less. However, due to the narrow focus of self-care on individual characteristics, recognized social determinants of health such as income and education level were seen as "individual factors" and therefore, removed the broader context affecting self-care and HF outcomes. To address this, further theoretical work should draw critical and constructivist frameworks to expand the understanding of the environment and its influences on HF self-care.

Additional conceptual and theoretical work is also needed to better understand how nurses support and impact self-care. Existing theories that guide nursing care situate HF self-care within the realm of the self and, while it touches on dyad and relational factors, it does not recognize the role of nurses in self-care itself (Riegel et al., 2016; Vellone et al., 2019; Attallah et al., 2021). As a result, a number of problems arise. First, both research and practice tend to

focus on patient deficits. The focus of nursing care, then, is on "fixing" these deficits by providing education and increasing motivation (Entwistle et al., 2018). Such a narrow focus on the patient as the site of intervention ultimately ignores how nurses shape the experience of HF, it overlooks existing strengths and possibilities, and most important, it overlooks the system-level structures that are necessary to support patients living with HF. Second, when the nursing role is not fully developed and understood, nurses in practice implement self-care support how they see fit. In other words, nurses tend to support self-care with a biomedical focus. This phenomenon has been studied, and researchers have found that nurses tend to pay little attention to social and structural determinants of health when providing self-care support (Maten-Speksnijder et al., 2016). In other words, by default, nurses tend to focus their practice on the person and as such, they risk missing the most important barriers to self-care in the process. Third, when self-care support is not fully conceptualized within a nursing framework, there is a risk to consider self-care support as falling outside the scope of the nursing discipline or, worst, belonging to caregiving exclusively.

One final consideration for theory is the need to dive more deeply into the rationales underpinning the self-care discourse and uptake in HF. More specifically, to question the economic imperative that is *part of* self-care. From a nursing perspective, it is important to question this imperative and advocate for patient-centred approaches that address patient needs, reduce inequities, and uphold shared accountability for HF outcomes. Ethical analyses could provide another useful avenue to critically analyze self-care interventions and question whose interests are being targeted, who benefits, what are potential harms, and who is responsible for balancing these risks and benefits in practice and how?

5.2 Recommendations for Research

I come to similar conclusions when it comes to research because, like theory, HF self-care has been and continues to be investigated primarily from an individualistic and biomedical perspective. The main question driving HF self-care research is: How do we enable patients to successfully uptake HF self-care behaviours? This form of questioning explains why so many studies emphasize compliance as a marker of success. However, as previously mentioned self-care success is often limited to biomedical outcomes and does not account for the patient perspective. In fact, biomedical outcomes and patient outcomes do not always align. The way research questions are framed ultimately has important implications for the ways in which interventions are developed, studied and measured. As such, I recommend that further research is needed to understand the gaps in existing intervention and evaluation research associated with HF self-care.

As previously mentioned, heart failure self-care interventions can be grouped into the three following categories: increasing knowledge, increasing motivation, and providing practical tools (Jaarsma et al., 2012). While these are important to manage HF symptoms and prevent disease progression, such interventions are implemented with objective and measurable biomedical end goals in mind (Morgan et al., 2016). Significantly less is known about how best to support patients living with HF to align care with quality of life or wellbeing goals – i.e., living well with the condition, reducing harms, and reaching a subjective sense of wellbeing. How can we provide nursing care that prioritizes what matters to patients in relation to their HF (and not vice versa)? In other words, how can we intervene in ways that place the patient before the diagnosis? More work needs to be done to understand how to create a mutually respectful

partnership that is influenced by the patient's goals and needs rather than healthcare goals and economic imperatives.

In the analysis, the outcomes of HF self-care were found to be almost entirely objectively measured with disease-control and biomedical markers in mind. If quality of life was an outcome, it was measured with a validated instrument. Adding to what was mentioned above, more work needs to be done to understand various aspects of living well with HF and what it means to undertake and incorporate self-care from the patient's perspective. A qualitative study by Kralik and colleagues (2010) designed to understand the meaning of self-care from the point of view of the patient found that success meant reclaiming a sense of order, envisioning a new future, and transforming at their own pace within the context of their life and illness. Therefore, indicators of successful self-care should align with patient understanding of self-care, and measures or reports of success should incorporate various aspects of living well. This is not to say that biomedical markers should be forgotten or ignored. However, broader interpretations should be investigated so that criteria for self-care outcomes can be considered beyond the individual's disease control.

Just as with theory, there appears to be a significant gap in understanding the implementation of HF self-care interventions within systems. Because there is so much emphasis on the individual nature of HF self-care, there is less significance placed upon understanding the ideal location, intensity, duration, and/or healthcare providers that should be involved in the delivery of interventions. This is problematic because healthcare decision-makers may haphazardly implement siloed resources that do not benefit patients. According to Butler and Kalogeropoulous (2012), the literature is replete with HF interventions that have not improved post-discharge outcomes, and that the "enormous resources spent by hospitals to randomly

implement unproven interventions would be better spent on actually studying what the real determinants of HF hospitalizations are and which interventions will prove to be beneficial" (p. 616). As the prevalence of HF is projected to increase over the next decade, it is essential to investigate HF self-care interventions in relation to the systems within which they are delivered.

Finally, critical scholarship focusing on the underlying assumptions of self-care related to autonomy, empowerment, choice, and control is much needed in nursing. There is no evidence to support that self-care lies within the person. In fact, the concept analysis uncovered contrary evidence to suggest that shifting the responsibility onto the patient living with HF and their care partner is an extension of neoliberalism. It goes hand and hand with the cost-cutting imperative. Considering that people diagnosed with heart failure tend to be older, face significant precariousness, require additional supports, experience multiple health issues, it is critical to ensure that systems are not offloading the responsibility away from healthcare systems and onto them – and their care partners who tend to face significant challenges as well. Furthermore, it is important to advocate for patients' rights to struggle with or reject prescribed behaviours that may take away from their quality of life or wellbeing and prioritize what matters to them. Critical scholarship could contribute to the development of a counter-discourse to reclaim autonomy under a new lens – one that is grounded in the lived experience of HF.

5.3 Recommendations for Practice

The impetus for conducting this concept analysis began when I was hired to develop and implement a heart function program in Fredericton, New Brunswick. While the work of program development and implementation was my responsibility, key performance indicators were already predetermined by the employer. Unsurprisingly, they were entirely driven by cost savings indicators such as reduced hospitalization and emergency department visits. The only

resource allocated to this program was one registered nurse. The program was initially entirely siloed from pre-existing resources, such as discharge planning, social work, dietetics, and chronic disease homecare programs. Furthermore, the idea of an educational program to support HF self-care was uncritically presented and accepted as empowering and patient-centred. While the work that I continue to do at the heart function clinic is ostensibly good, I questioned how economic imperatives influence the care that nurses plan and deliver. I further wondered how we could support patients who cannot or decide not to engage in traditional chronic disease management programs. With this perspective and my findings in mind, I have determined certain recommendations that can potentially improve heart failure self-care in practice.

One particularly important aspect of practice that should be addressed immediately is the dichotomizing of self-care actions as good or bad, effective or failed. The concept analysis found that people who were unable to achieve self-care metrics were described as poor, ineffective, inadequate, non-adherent, non-compliant, and unsuccessful (Abotalebidarisasari et al., 2016; Moser & Watkins, 2008; Ruppar et al., 2018; Hwang et al., 2020). It is incredibly important to acknowledge that self-care is a demanding and difficult process that waxes and wanes over time depending on many factors, including many factors that are not within the realm of the patient. Patients do not fail but rather make decisions that align with their needs and circumstances – and that is possible for them given their available resources and supports. They also juggle competing priorities. Persuading patients to uptake predetermined self-care behaviours and then labelling those who do not follow the advice is harmful, and it hinders a truly supportive patient-nurse relationship built on trust and communication. It also further reinforces the power dynamics at play in this relationship, which may further disenfranchise patients who are trying their best to learn to live well with a complex and fluctuating condition (Kendall et al., 2011).

More broadly, and to address immediate practice-related issues, guiding documents for HF practice in Canada should be reviewed and updated to reflect nursing practice. As previously mentioned in Chapter 2, the Canadian Cardiovascular Society (CCS) and the Canadian Heart Failure Society (CHFS) are the primary organizations who develop guidelines and recommendations for heart failure practice in Canada. However, despite their intent to guide interdisciplinary practice, their work primarily targets physicians. For example, the CCS is entirely comprised of medical doctors and clinician scientists, and the CHFS executive committee has only one nurse practioner representative. Furthermore, the updated CCS HF guidelines (2021) had only medical doctors on their primary panel, and only two nurse practitioners on their secondary panel. The near absence of a nursing perspective at the national level is concerning, particularly considering Virani and colleagues (2020) findings that 98% of HF clinics across Canada offered nursing support and that nurses were found to be primarily responsible for patient education. The work of HF nurses is further obscured by national guidelines reducing self-care to "behaviours that adhere to recommendations" (CCS, 2016, p. 307). Despite my analysis findings that HF self-care is multifaceted and complex, this understanding is not reflected in practice guidelines. As such, considerable effort is needed at the national level to develop guidelines that reflect nursing practice.

A national HF nursing framework could attend to a number of the currently identified shortcomings. Despite the expansion of the HF nurse role over the past two decades, the understanding of what it constitutes and how to implement HF nursing care varies across the country. Framing HF nursing support beyond disease-oriented intervention would further elucidate the important role of HF nurses and more clearly identify the self-care needs of those living with HF. As identified in the analysis, the self-care experience is compounded by a range

of factors beyond the realm of the individual. As such, a nursing framework would be able to take these often overlooked aspects into consideration so that nursing support could align with the reality of HF self-care. This would not only better guide practice, but also help to integrate HF nurse specialists into the system where there is an identified need. For example, heart failure nursing care could include transitional care between hospital and home, homecare programs, and support to caregivers. This may help to implement a more fulsome and integrated HF management strategy and prevent siloed disease-oriented programs that are isolated within the community. A national nursing framework would therefore be able to increase consistency in defining the role of HF nurses and in integrating HF nurses within currently existing systems.

A nursing specific HF self-care framework could also be the impetus for the development of guiding documents that allow nurses to reflect upon their practice and consider how they support self-care. Whereas our current understandings of HF support are biomedically driven and focused, I believe that framing our work with guiding documents would move nurses work toward a more holistic perspective *within a nursing context*. This would also allow nurses to reflect on their practice and identify gaps in knowledge from a nursing perspective, so that they can seek opportunities to address learning needs.

Finally, CCS (2016) guidelines currently recommend screening for anxiety, depression, cognitive impairment, and literacy levels. While these screening tools can be valuable, they do not shed light on social and structural determinants that may be more influential on self-care practices. As such, there is value in screening for multiple domains of social risk, such as poverty, food insecurity, and housing insecurity. Identifying social determinants of health that may impede self-care allows nurses to identify appropriate interventions for the individual, but also allow nurses to align system resources with identified needs. This could help promote

health equity in practice, while also inductively identifying social and structural influences to better guide research.

CONCLUSION

The purpose of this study was to explore the evolution of the concept of self-care in HF, identify and describe the antecedents, attributes, and consequences of HF self-care, to critically analyze the uptake of the concept, and discuss the implications of the findings for theory, research, and practice. Another objective was to critically analyze the concept of self-care in HF from a different standpoint than the predominant postpositivist and biomedical perspective, which currently dominates the literature. This concept analysis was completed at an interesting time in nursing as more questions are raised about knowledge production, colonization, and the centering of nursing theories on Western and Eurocentric ideologies.

Given this perspective, I was able to raise important conceptual questions about the use of the concept of HF self-care, its meanings, and its function. I found that HF self-care was primarily conceptualized as an individual process regardless of circumstances. This has implications for nurses to address contextual elements that influence self-care, including individual, relational, and system factors. The significant emphasis on individualism not only obscures social and structural determinants of health in practice but further influences research that is undertaken. Namely, research was found to primarily focus on ways to change behaviour. Furthermore, the concept of self-care is underpinned by neoliberalism, in that individuals are costly burdens who must learn to manage their condition. This raises questions about the economic imperatives that may take over nursing care at the peril of the patients' actual needs.

I know firsthand that nurses who specialize in heart failure management aim to provide care that is scientifically sound while also aligning with patient needs and, more broadly, with the aims of the nursing discipline. However, this concept analysis did reveal significant conceptual problems that may undermine nurses' effort to provide holistic, ethical, and patient-

centred care. Moving forward, it is important to adopt a more robust conceptualization of HF self-care that reflects the current state of knowledge and the aims of the nursing discipline.

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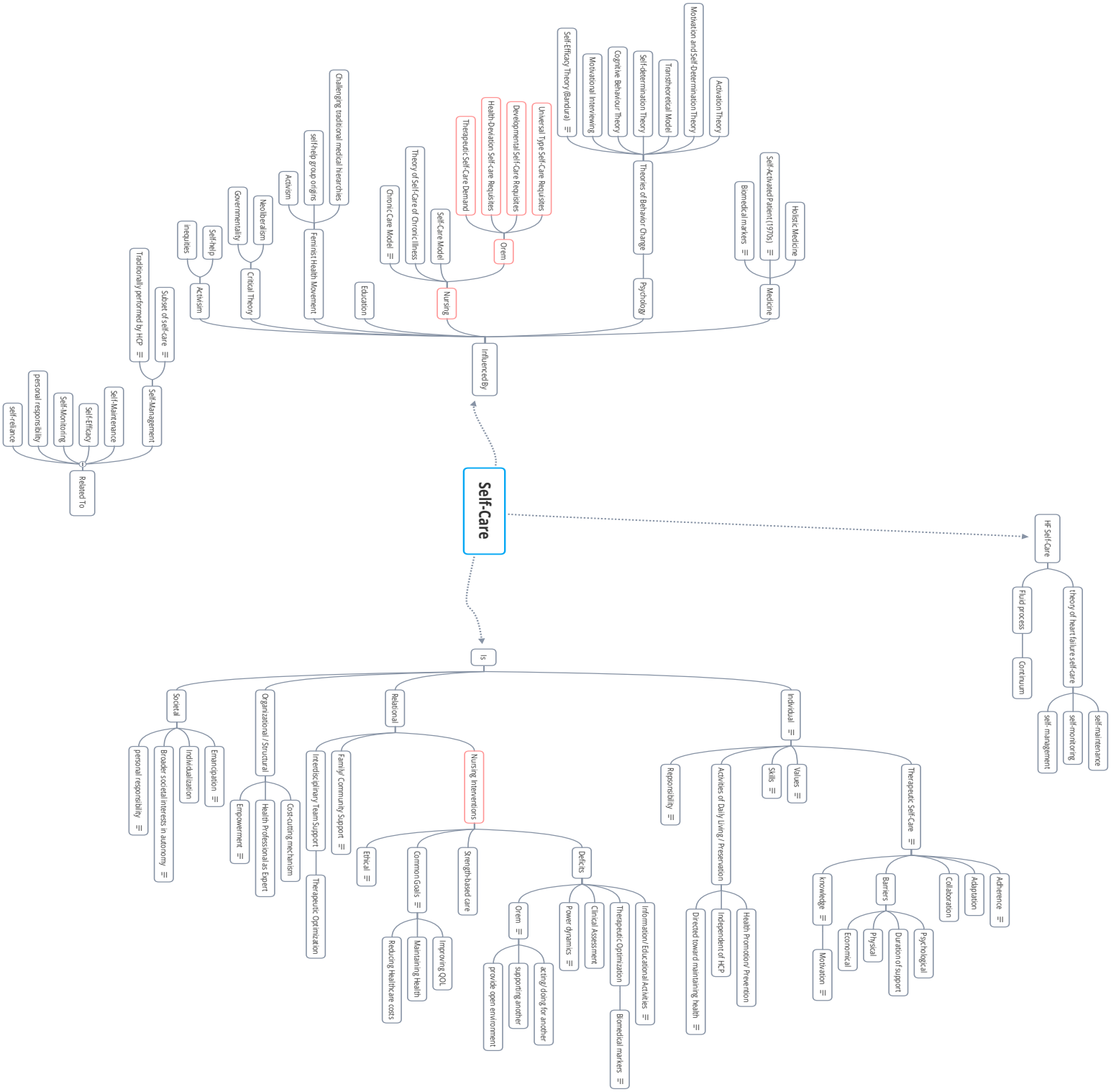
Appendix A

Self-Care Mind Map for Literature Review



Appendix B

Selected Sample of Concept Analysis

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