

# Advance Care Planning in Advanced Heart Failure: A Relational Exploration of Autonomy

by

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Lawrence S. Bloomberg Faculty of Nursing  
University of Toronto

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## Abstract

Advance care planning (ACP) is the process of understanding and sharing personal values and goals to ensure people with serious illnesses receive healthcare and treatment that is consistent with their goals and preferences. With the increasing number of treatment options available to patients living with advanced heart failure (HF), ACP is regarded as a means of preserving individual autonomy throughout the illness trajectory. Despite significant public awareness campaigns, research and interventions developed to increase participation in ACP, this practice remains severely under-utilized by those who are chronically ill. This gap in practice highlights the need for further exploration of how patients, families and healthcare providers (HCP) engage with ACP as a practice that is intended to promote patient autonomy. Therefore, the aim of this research was to gain an understanding of how patients, families and healthcare providers (HCP) understand and express their autonomy within the process of ACP. Critical qualitative multiple case study methodology, guided feminist ethics and relational autonomy, was used. Patients with advanced HF were purposefully recruited from two sites; cases were constructed using data from 19 interviews with seven patients, eight caregivers, and nine HCPs. Constructions of autonomy were developed using within and across-case analysis, guided by relational conceptualizations of autonomy. There were three key findings that resulted from this study. First, ACP is understood

as external to treatment decision making within the current biomedical landscape, with a specific focus on the power of the legal model. Second, the experience of autonomy in advanced HF is incongruent with the dominant individualistic approach and instead, is a relational experience that is based on relationships of trust. Finally, ACP is influenced by interpersonal relationships and responsibilities as well as interpersonal and social power dynamics. Although ACP is considered a practice that preserves individual autonomy, interpersonal, institutional and societal level relationships were all heavily influential in this practice. Future research and practice endeavors should consider the advancement of ACP (and the enactment of autonomy) using a relational framework that acknowledges autonomy is experienced within the context of institutional, social, and interpersonal relationships.

# Dedication

This thesis is dedicated to Dorothy Sullivan and Louise Killackey, my two favourite nurses who inspired this work and showed me what it means to be resilient in life and realistic about death.

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## List of Abbreviations

ACD or	Advanced Care Directive or
AD	Advanced Directive
ACP	Advance Care Planning
CAD	Coronary Artery Disease
CABG	Coronary Artery Bypass Grafting
CPR	Cardio-Pulmonary Resuscitation
CRT	Cardiac Resynchronization Therapy
DNR	Do Not Resuscitate (order)
EF	Ejection Fraction
EOL	End of Life
GOCD	Goals Of Care Discussion
HCP	Health Care Provider(s)
HF	Heart Failure
JVP	Jugular Venous Pressure
IC	Informed Consent
ICD	Implantable Cardioverter-Defibrillator
ICU	Intensive Care Unit
LST	Life-Sustaining Treatments
LVAD	Left Ventricular Assist Device
MAiD	Medical Assistance in Dying
MCS	Mechanical Circulatory Support

NYHA	New York Heart Association
PC	Palliative Care
PCI	Percutaneous Coronary Intervention
POA(PC)	Power Of Attorney (for Personal Care)
PM	Pacemaker
SDM	Substitute Decision Maker(s)
TAVI	Transcatheter Aortic Valve Implantation
TAVR	Transcatheter Aortic Valve Replacement



# Glossary

<b>Advance Care Planning</b>	Advance care planning (ACP) enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers. ACP also addresses individuals' concerns across the physical, psychological, social and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions. (Rietjens et al., 2017)
<b>Advanced Care Directive or Advanced Directive</b>	Advance directives indicate whom the patient would want to make treatment decisions on his or her behalf and what interventions the patient would or would not want in various situations. An advance directive is referred to in law by various names: "advance directive " (British Columbia, New Brunswick & Yukon), "personal directive" (Alberta, Nova Scotia & Northwest Territories), "health care directive" (Saskatchewan, Manitoba & Newfoundland), "advance care plan" (Ontario), "mandate in case of incapacity" (Quebec). (Virtual Hospice, 2019)
<b>Advanced Heart Failure</b>	A progressive stage of heart failure when conventional cardiac therapies and symptom management strategies no longer work, distinguished by the fact that patients experience symptoms such as shortness of breath and palpitations at rest, display marked limitation of physical activity, and fatigue easily.
<b>Cardiac Resynchronization Therapy</b>	Also called a biventricular pacemaker, this type of therapy can be provided alone or in conjunction with a defibrillator in order to improve cardiac output by synchronizing the contraction of both ventricular chambers.
<b>Coronary Artery Disease</b>	A disease in which atherosclerotic plaque accumulates in the coronary arteries, resulting in decreased blood flow to cardiac tissue.
<b>Cardiopulmonary Resuscitation</b>	A technique that combines chest compressions with artificial ventilation in an effort to manually preserve circulation and brain function for a person who has experienced cardiac arrest.
<b>Do Not Resuscitate Order</b>	Also known as "no code" or "allow natural death," a "do not resuscitate" order is a legal order written either in the hospital or on a legal form to withhold cardiopulmonary resuscitation (CPR) or advanced cardiac life support (ACLS), in respect of the wishes of a patient in the event of a cardiac arrest.
<b>Goals of Care Discussion</b>	A conversation undertaken during an illness to ensure medical care is based on a shared understanding of the illness and on the patient's goals, wishes and values.

<b>Implantable Cardioverter-Defibrillator</b>	A device that is implanted inside the body and is able to perform cardio-version, defibrillation, and pacing of the heart in order to correct life-threatening cardiac arrhythmias.
<b>Heart Failure</b>	A chronic, progressive and terminal cardiovascular disease, which is characterized by weakened or damaged cardiac tissue resulting in the hearts inability to pump blood efficiently.
<b>Left Ventricular Assist Device</b>	A left ventricular assist device is a type of mechanical circulatory support device. It is a mechanical pump that is implanted in patients who have heart failure to improve the cardiac output by supporting the weakened left ventricle.
<b>Living Will</b>	A document which outlines an individual’s wishes in the event that they become ill and cannot communicate their wishes about treatment. For example, people may write a “living will” saying that they do not want to be kept alive on artificial life supports if they have no hope of recovery. This term is also used interchangeably with “advanced directive”.
<b>Life-Sustaining Treatments</b>	Replace or support failing organ systems in order to prolong life. Commonly used life-sustaining treatments include CPR, mechanical ventilation, dialysis, enteral feeding, and artificial hydration.
<b>Mechanical Circulatory Support</b>	A specific type of LST developed for heart failure patients that replaces or supplements the function of the heart. These include ventricular assist devices and total artificial hearts.
<b>MitraClip® Procedure</b>	Also called transcatheter mitral valve repair, a new procedure that allows the mitral valve to be repaired in a patient using a catheter. This procedure is less invasive than traditional valve repair surgery and is therefore available to an older cohort of HF patients who would not be candidates for standard cardiovascular surgical procedures.
<b>Myocardial Infarct</b>	The irreversible death of heart muscle secondary to prolonged lack of oxygen supply.
<b>Percutaneous Coronary Intervention</b>	Formerly known as angioplasty with stent, this is a non-surgical procedure that uses a catheter to place a stent in the coronary arteries in order to open up blood vessels in the heart that have been narrowed by atherosclerosis.
<b>Power Of Attorney (for Personal Care)</b>	A legal document that gives someone else the power to make personal care or healthcare decisions on behalf of another person, if that individual is incapable of making decisions on their own.

<b>Pacemaker</b>	A cardiac device, which is surgically implanted and uses electrical impulses, delivered by electrodes contracting the heart muscles, to regulate the beating of the heart. The primary purpose of a pacemaker is to maintain an adequate heart rate.
<b>Relational Autonomy</b>	A cluster of approaches to autonomy that emphasize the socially embedded nature of agents and view the ability to be self-directed as influenced by social and political forces. This approach understands agents' identities to be formed within the context of social relationships and shaped by complex intersecting social determinants (McLeod, 2002, McLeod & Sherwin, 2000; Sherwin, 1998).
<b>Social Location</b>	Consists of ascribed social identities (i.e. gender, race, sexual orientation, ethnicity, kinship status), and social roles and relationships (i.e. occupation, political party membership, familial positioning, etc.) (Grasswick, 2013).
<b>Substitute Decision Maker</b>	A person who makes decisions on behalf of another person, whether legally appointed using POAPC documentation or informally using the SDM hierarchy from the Substitute Decisions Act (Ontario, 1992)
<b>Transcatheter Aortic Valve Implant (TAVI)</b>	A procedure that allows a new aortic valve to be implanted in a patient using a catheter. This procedure is less invasive than traditional valve replacement surgery and is therefore available to an older cohort of HF patients who would not be candidates for standard cardiovascular surgical procedures.

## Preface

The history of advance care planning is inextricably linked with the history of cardiopulmonary resuscitation and “do not resuscitate” (DNR) orders as established healthcare practices in high income countries. Beginning in the 1950s, cardiopulmonary resuscitation (CPR) was developed and began to be used across healthcare settings, marking the beginning of a significant era in modern healthcare delivery (Bishop, Brothers, Perry, & Ahmad, 2010; DeBard, 1980). Initially, CPR was primarily used during the intra-operative and post-operative periods to revive patients who had suffered cardiac or respiratory arrest (Bishop et al., 2010). Prior to this, if a patient experienced an arrest during or following a surgical procedure, healthcare providers would allow the patient to die. With the advent of CPR, providers were able to resuscitate patients to recover from surgical procedures and live longer with the support of life-sustaining treatments (LST) provided in the intensive care unit (ICU) (Bishop et al., 2010). The 1960s and 1970s were therefore characterized by the increasing use of ICUs, and LST such as mechanical ventilation and CPR quickly became widespread (Bishop et al., 2010).

At the same time, the consumer rights movement began in the United States (Bishop et al., 2010). This social movement was primarily concerned with protecting the rights of consumers who were being provided services and products. This movement sparked an increased interest in patients’ rights, with a strong focus on the social discourse of death and dying. As this movement developed so did the understanding that CPR was not necessarily useful for all patients experiencing cardiopulmonary arrest, as it often prolonged an inevitable death with a limited chance of success (Bishop et al., 2010). The consumer rights movement was significant in highlighting the right of patients to refuse medical intervention or withdraw medical treatment as consumers of these therapies. Up until this point, consent for CPR had been presumed, but the consumer rights movement triggered the development of DNR orders, which would allow people to avoid unwanted resuscitation<sup>1</sup>. Therefore, this time period identified a need for further

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<sup>1</sup>Originally, advanced directives were synonymous with DNR orders. This is demonstrated through the SUPPORT trial (Connors, Dawson, Desbiens, et al. 1995) outcome measurements and will be discussed further in the literature review.

development and direction from the public in regard to the issue of resuscitation and advanced consent for LST (Bishop et al., 2010).

Resulting from this social and political discourse, the concept of a living will was first developed in the United States in the late 1960s. The goal of a living will was to provide a way for people to exert their individual autonomy by controlling treatment choices beyond the point at which capacity may be lost. This goal was achieved through outlining specific preferences regarding LST in a legal document, called a ‘living will’ or ‘advanced (care) directive’. Following a number of controversial, contentious and highly publicized legal disputes regarding the withdrawal of LST throughout the 1970s and 1980s, the United States passed the Patient Self-Determination Act (PDSA) in 1990 (H.R. 449 – Patient Self Determination Act of 1990, 101<sup>st</sup> Congress). This act mandated healthcare organizations (specifically, hospitals, skilled nursing facilities, home health agencies, hospices, and prepaid health care organizations) to do five things (Sabatino, 2010):

1. Provide written information to patients concerning their right under state law to make decisions about their medical care and the right to formulate advance directives.
2. Maintain written policies and procedures regarding advance directives and make them available to patients upon request.
3. Document whether or not the patient has executed an advance directive.
4. Comply with the requirements of state law respecting advance directives.
5. Educate staff and community on advance directives

(Sabatino, 2010, p. 217)

The PDSA demonstrates the integral link between healthcare practices and political context. By mandating the ACP process across publicly funded organizations in the US, this legislative act was developed in conjunction with the capitalist and neoliberal government at the time in order to obligate patients, providers and institutions to promote individual autonomy (Greco, Schulman, Lavizzo-Mourey, Hansen-Flaschen, 1991).

In Ontario, the Substitute Decisions Act (Substitute Decisions Act, 1992, S.O. 1992, c. 30) and the Healthcare Consent Act (Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A) were passed, legislating the appointment of a substitute decision-maker (SDM) to make decisions in

the best interest of another person in the event that they become incapable of making their own healthcare decisions. In Ontario, SDMs are appointed using the Power of Attorney for Personal Care (POAPC) documentation. If a person does not have a POAPC appointed, the SDM is appointed based on a pre-established hierarchy which moves through various family relations and then finally onto the Public Guardian and Trustee if the person has no available relatives. Importantly, in Canada, “legislation varies from province to province with respect to the scope of ADs, who can act as proxy for the patient, requirements for witnessing the ADs, procedures for activating the AD, etc.” (Singer, Robertson & Roy, 1996, p. 1690). In Ontario, ADs are not legally binding documents, and in the event that one is unable to consent to treatment, the responsibility falls on the SDM to provide informed consent, given the best interests of their loved one and their previously expressed wishes (HCCA, 1996; SDA, 1992). This means that in Ontario, ADs are only used to help inform SDMs in the event that a substituted decision must be made; they do not act as advanced consent for treatments or withdrawal of treatments.

More recently, due to the shifting demographics of the Canadian population, which includes a rapidly growing cohort of seniors, increasing rates of chronic disease and increasing healthcare costs at the end of life (EOL), the National Taskforce for Advance Care Planning was initiated in 2013 through the Canadian Hospice and Palliative Care Association (Statistics Canada, 2017; Canadian Hospice and Palliative Care Association, 2013). This taskforce implemented the “Speak Up” campaign, a public awareness campaign seeking to increase participation in ACP through education and resource provision. This campaign is ongoing today, and provides resources for patients, families, and healthcare providers as well as online documentation of advance care plans. Around this time there was also a resurgence in academic research and institutional policy regarding the implementation of ACP in Canada, demonstrating the renewed need for improved decision making and EOL care for Canadian patients and their family members.

Finally, in 2016 the Canadian Supreme Court legislated Medical Assistance in Dying (MAiD), which provides Canadians with the right to request assistance in dying under specific circumstances (Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), First Session, Forty-second Parliament, 2016). This

legislation was primarily justified using the principles of respect for personal autonomy, protection of individual rights and the promotion of personal choice. This was, and continues to be, a significant turning point in the history of Canadian politics, healthcare and ethics, and is largely supported by the continued neoliberal rhetoric of individualism, the right to self-determination and the promotion of patient choice. Some authors have examined the idealized concept of promoting patient empowerment through providing ‘choice’ in the healthcare setting (Draught & Koenig, 2002; Mol, 2008), and have argued that empirical evidence does not support the autonomy paradigm of patient choice that is currently used in EOL decision making (Draught & Koenig, 2002). The MAiD legislation has highlighted some of these tensions, and the challenges with these concepts will be discussed further in Chapter 3.

The MAiD legislation is also especially significant because Canada is the only jurisdiction to allow nurse practitioners to legally provide medical assistance in dying (Elmore, Wright, & Paradis, 2016). Although I did not explicitly explore MAiD in this research, it is important to acknowledge the association between these two healthcare practices, although due to the novelty of MAiD in Canada the nature of this relationship is still unclear. The majority of the literature on ACP and MAiD focuses on the role and perspective of the physician, there is a need to explore and highlight the opportunities available to the nursing profession to enhance care for HF patients throughout the disease trajectory and through EOL care through involvement in both ACP and MAiD. Restrictions still apply for patients who would like to use ADs to consent in advance for MAiD in Canada, as this is currently being examined but is not legislated. Overall, the social discourse surrounding the legalization of MAiD and the implementation of this practice continues to evolve and is a factor that shapes the current context, understanding and perception of ACP in Canada.

## Reflexive Conclusion of Preface

At this final stage of the research process, I continue to reflect on my choice of research topic, the development of the research, and the impact that the results will have. Although professionally I define myself as a registered nurse, I have realized that my choice of research topic has been influenced not only by my experiences as a nurse working in cardiac care, but by my social location and the many relationships that shape my identity. I was drawn to this topic initially because of how strongly I believed in the principle of autonomy and the idea of informed consent. As a well-educated and privileged white woman in North America, the concepts of choice, control and empowerment resonated with the way that I understood decision making within my own life. That slowly began to shift as I began my career in a complex healthcare system that often left me feeling complicit in providing nursing care that I could only understand as harmful. This felt counterintuitive to the reasons I was drawn to the profession initially and has fueled my determination to better understand how the concept of consent can become so discrepant with the reality experienced by patients.

As someone who defines myself by the important relationships in my life, the perspectives offered by feminist bioethics felt immediately familiar and reflective of the realities of providing nursing care. The primacy of relationships and the challenges of proximity and vulnerability spoke to me and provided a framework within which to consider the many decisions people make throughout life, especially within the context of a chronic illness. Personally, watching my grandmother, a nurse and feminist in her own right, receive a cardiac device that did not align with her ultimate goals in life and experiencing the long-term repercussions of that treatment decision has been incredibly influential in this pursuit and my understanding of advance care planning. Professionally, my social location as a nurse working with cardiovascular patients and their families in a variety of settings has influenced my interest in this topic, and my professional positioning shaped the relationships I developed with the participants, as I understood their experiences through the lens of my own professional background and training. Ultimately, this process has been a constant navigation of my various identities, and it is this collection of identities that has allowed me to develop this research and approach this topic from a unique perspective



# Chapter 1

## Introduction

In the introduction to this thesis, I first outline the current burden of heart failure in the Canadian healthcare system. I will then situate this study within the current landscape of advance care planning and highlight the need for advance care planning in the heart failure population. Next I will present the research questions guiding this study and will conclude the introduction by providing an overview of the upcoming chapters in order to situate the reader for the remainder of this thesis.

### 1 Heart Failure in Canada

In Canada, cardiovascular disease is the leading cause of hospitalization and the second leading cause of death (Statistics Canada, 2017). Heart failure (HF) is the end result of many common cardiovascular diseases such as hypertension, coronary artery disease, myocardial infarct and cardiac arrhythmias (American Heart Association, 2015). It is a chronic, progressive and terminal cardiovascular disease, which is characterized by weakened or damaged heart muscle resulting in the heart's inability to pump blood efficiently. This decreased cardiac function results in HF patients experiencing symptoms such as shortness of breath, fatigue, decreased appetite, social isolation and depression (MacIver, Wentlandt & Ross, 2017).

There are currently more than 600 000 Canadians living with heart HF and more than 50 000 patients newly diagnosed with HF annually (Heart and Stroke, 2016). As more Canadians survive cardiovascular diseases due to improvements in diagnostics and management, the prevalence of HF continues to rise (Heart and Stroke, 2016). HF treatment and management currently account for 2.8 billion dollars of Canadian healthcare spending per year (Heart and Stroke, 2016). This significant economic cost is due to the unpredictable nature of the illness trajectory and the need for frequent unplanned hospitalizations during periods of acute disease exacerbation (Heart and Stroke, 2016). In addition to this, HF patients represent significant pharmaceutical spending due to the medications required for optimal symptom management, as well as increasing costs related to medical device usage.

There are three main types of cardiac devices that have been successfully integrated into standard HF care: cardiac resynchronization therapy (CRT), (also called biventricular pacemakers (PM), implantable cardioverter defibrillators (ICD), and mechanical circulatory support (MCS) (Sacks, Jarcho, & Curfman, 2014). MCS, which was initially introduced as a therapy to bridge patients to receiving a heart transplant, is now also being used as destination therapy to permanently support patients until the EOL. Destination therapy is a growing option for patients who may not be considered candidates for cardiac transplantation due to advanced age or multiple co-morbidities, and also addresses the imbalance between the number of patients with advanced HF and the number of hearts available for transplantation (Gal & Jaarsma, 2013). All three types of devices have demonstrated reduced mortality in HF. Less invasive therapies, such as transcatheter aortic valve implantation (TAVI) or replacement (TAVR) and devices such as the MitraClip® are rapidly changing the treatment of patients with HF caused by severe symptomatic aortic or mitral regurgitation (Asgar et al., 2019). TAVI and MitraClip® are now the standard of care for patients believed to be at high surgical risk and are considered reasonable alternatives to surgical valve replacement for those at intermediate surgical risk (Asgar et al., 2019; Franzen et al., 2011).

Patients with advanced HF face many incredibly complex decisions along the trajectory related to medications, device options, non-invasive therapies as well as heart transplantation or MCS (Matlock, McGuire, Magid, & Allen, 2017). Research suggests that patients often have limited involvement in these decisions, and may not have an in-depth understanding of the risks and benefits of each medical option, which further decreases their ability to participate in decision making (Matlock et al., 2017).

Cognitive impairment is highly prevalent in the HF population, with many studies suggesting that the majority of HF patients suffer from at least mild cognitive impairment and up to 25% having moderate to severe cognitive impairment (Yzeiraj, Tam & Gorodeski, 2016). The cause of cognitive impairment in HF is not clear but may be related to factors such as reduced cerebral blood flow due to decreased cardiac output, hypertension, sleep apnea and depression (Yzeiraj et al., 2016). Because cognitive impairment is manifested through problems with memory,

executive function and problem solving (Yzeiraj et al., 2016), HF patients often rely heavily on family members and others for social support and self-care management support (Graven & Grant, 2013). Family, friends and healthcare practitioners provide informational, emotional and tangible support to HF patients, allowing them to maintain their self-care routines (Graven & Grant, 2013). Additionally, family members support daily self-care activities such as medication and diet adherence, fluid restrictions, weight surveillance, etc. (Graven & Grant, 2013). Importantly, families also play a pivotal role in the decision making process in HF by monitoring symptoms and encouraging patients to seek treatment through the provision of both informational and appraisal support (Graven & Grant, 2013; Friedman & Quinn, 2008). Overall, these studies demonstrate the highly relational nature of daily management of HF in addition to the role that external social support has on the decision making processes of HF patients. Despite these results, the dominant model of decision making continues to be centered on respect for individual autonomy and employs the singular process of informed consent.

The last six months of life for HF patients are associated with frequent hospital admissions, invasive procedures and intensive care admissions (Goodlin, 2009; Ko et al., 2008). This trajectory most often results in a hospital death, despite evidence that most HF patients prefer supportive care over intensive intervention at the EOL and want to die at home (Formiga, Ortega, Casas, Ramon, & Pujol, 2004). ACP is often framed as a practice that can mitigate these negative outcomes by ensuring care providers are aware of patient preferences prior to entering the EOL phase. Overall, the unpredictability of the HF illness trajectory combined with the complex health decision making required by patients and families characterizes this population as one that would benefit from advance care planning (ACP). The goal of ACP in this population is to align patient and family preferences with the healthcare they receive and reduce unnecessary hospitalizations and intensive or harmful intervention (Allen et al., 2012).

## 2 Current Landscape of Advance Care Planning

In this section, I briefly situate advance care planning (ACP) within wider political, social, legal and ethical contexts. The specific contexts discussed include contemporary liberal and neoliberal ideologies, the history of the biomedical model with a focus on individualism, the development and increasing use of life-sustaining treatments (specifically in HF management), the shift in

current social discourses about healthcare decision making and the emphasis on promoting self-determination and autonomy as an inherent moral good.

## 2.1 Liberalism and Neoliberalism

Liberalism can be understood as a complex phenomenon composed of economic, political and ideological discourses that influences the social organization of modern society (Jessop, 2002). Liberalism claims “economic, political and social relations are best organized through formally free choices of formally free and rational actors who seek to advance their own material or ideal interests” (Jessop, 2002, p. 453). This means that economically, liberalism supports the expansion of the market economy and politically, it calls for limited government intervention in economic and social spheres (Jessop, 2002). Overall, the goal of liberalism is to maximize personal freedom in all aspects of social life (Jessop, 2002).

Neoliberalism has been defined as a new economic project which calls for the “liberalization and deregulation of economic transactions” both within and across borders and the privatization of public enterprises and services (Jessop, 20002, p. 453). More broadly, neoliberalism refers to the dominance of capitalist markets and the free market model, comprised of the following philosophy:

1. Markets are the best and most efficient allocation of resources
2. Societies are composed of autonomous individuals motivated by material or economic considerations
3. Competition is the major market vehicle for innovation

(Coburn, 2000, p.138)

Based on these points, neoliberalism can be understood as a form of rule that supports individual freedom allowing agents to exercise their autonomy (Petersen, 1997). Neoliberal rationality emphasizes autonomy and the capacity to care for oneself, and calls upon individuals to pursue self-governance “through processes of endless self-examination, self-care and self-improvement” (Petersen, 1997, p. 195). Since the entry of neoliberalism into Western society in the 1970s, there has been a shift away from the idea that the state is responsible for the health and well-being of its citizens, towards the notion that individuals hold the responsibility to protect themselves from risk (Petersen, 1997). This discourse tends to overemphasize the role that

individuals hold in maintaining health by emphasizing the self-management of risk and promoting self-care, especially in chronic illness management, under the assumption that all agents have equal abilities to enact self-care strategies (Petersen, 1997). Neoliberal ideology has also supported the rise of healthcare practices such as informed consent and ACP using the justification of individualism and rational, autonomous agents to maintain supposed control over their healthcare. The role of neoliberal discourse in the provision of healthcare and its strong focus on individual autonomy, rights and freedom will be discussed further in the following section.

## 2.2 Biomedical Model

Current Westernized healthcare systems have been shaped by the biomedical model of disease, which dictates that illness is caused by individual cellular abnormalities (Azetsop & Rennie, 2010; Wade & Halligan, 2004). This model is known for conceptualizing health as the absence of disease, encouraging mind-body duality, and focusing on single cellular pathologies while avoiding social, cultural and economic contributors to health (Wade & Halligan, 2004). As a result, this model promotes medical individualism by dedicating specific treatments to specific patients based on individual pathologies. Historically, physicians made treatment decisions resulting in a paternalistic decision making model (Chin, 2002). Inspired by the consumer rights movement, consumerism, and the increasing influence of neoliberalism, recent decades have seen a shift away from paternalism towards promoting patient empowerment and personal involvement in health care decisions, which encourages patient self-direction. As a result, health care systems have been structured around the bioethical principle of respect for individual patient autonomy and have promoted self-governance as a priority (Azetsop & Rennie, 2010). Although the biomedical model has proven relevant for the treatment of many illnesses and is supported by significant empirical research, it has also been frequently criticized by feminists, multiculturalists, disability rights activists, and other critical scholars due to its narrow view of individuals, lack of holism and limited scope (Azetsop & Rennie, 2010).

Beauchamp & Childress' (2001) account of autonomy as the ability to be self-directed and free of controlling interference is theoretically embedded within liberalism and freedom, and therefore well aligned with the individualism promoted in the biomedical model predominant in

Westernized health care systems. This model of autonomy has prevailed in the majority of high-income societies, encouraged by social and political liberalisation. Campaigns for “patient-centred care,” “targeted treatments” and “personalized” genomic therapies are increasingly prevalent. Such discourse perpetuates ideas of individualism and patient empowerment, and continues to reject and ignore the role of social, political and relational forces on the health and well-being of citizens (Polzer & Power, 2016). These individualized practices have exaggerated patients’ capacity for agency and self-direction, and, in alignment with neoliberal principles, have shifted the burden of responsibility for health onto the individual while ignoring larger socio-political influences (Polzer & Power, 2016; Petersen, 1997).

The influence of the biomedical model on the ACP process will be explored further in the following section, with a specific focus on the HF population.

## 2.3 Advance Care Planning in Heart Failure Management

Advanced HF is most commonly defined using classification systems such as the New York Heart Association (NYHA) classification system, which is based on patient symptoms (see Appendix A), or the American Heart Association/American College of Cardiology staging classification, which is based on objective assessment (see Appendix B) (American Heart Association [AHA], 2015). HF is considered advanced when patients continue to experience symptoms such as shortness of breath, fatigue, palpitations at rest and display marked limitation of physical activity despite optimal medical therapy (NYHA Class IV or AHA Class D). Despite the advanced stage of disease, a number of treatment options exist for HF patients, including procedures such as coronary artery bypass grafting, valve replacements, PCI or TAVI; the implantation of devices such as CRT/PM, ICD or LVAD; heart transplantation; and inotrope infusions (AHA, Heart and Stroke, 2016).

An example of a challenging decision within the trajectory of advanced HF includes the decision to implant an ICD. Although this device does not reduce symptom burden, it does decrease the chance of sudden cardiac death. Therefore, this therapy may be beneficial for someone who values living as long as possible. However for those who prefer to die “naturally” by having their heart stop, receiving an ICD may not align with their goals of care. Research has demonstrated

that patients with advanced HF often do not understand their prognosis nor the function of the many complex devices used throughout the trajectory of HF management, which contributes to challenges experienced during decision making and the ACP process (Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2013; De Vleminck et al., 2014; Greutmann et al., 2012b; Kovacs, Landzberg, & Goodlin, 2013; MacIver et al., 2017).

In recent years, due to the rapid evolution of HF management techniques and therapies, ACP has become increasingly relevant for this patient population. The introduction of cardiac devices in the early 2000s has been identified as one of the most fundamental paradigm shifts in HF care (Sacks, Jarcho, & Curfman, 2014). Devices such as CRT/PM, ICD and MCS are becoming increasingly prevalent in the management of HF, but also further complicate prognosis in end-stage disease. Despite the benefit that these devices provide, they can also often cause great distress related to patient and family decision making throughout the disease trajectory and at the EOL. An example of this can be demonstrated through the case of ICD deactivation at the EOL. ICDs prevent sudden death either by anti-tachycardia pacing or through delivery of one or more defibrillator shocks (MacIver, Tibbles, Billia, & Ross, 2016). Patients with ICDs may experience shocks during their last days and hours of life, which can be painful for the patient and can be avoided by deactivating the device (MacIver et al., 2016). If a patient is incapable of consenting to device deactivation, this decision is left to the SDM, which can be distressing for family members. This is an example where ACP would be beneficial, as preferences for EOL care and discussions regarding device deactivation could be discussed with the HF patient and SDM in advance.

Current HF management guidelines recommend that ACP be initiated early and often in the disease trajectory; most recommendations favour a proactive approach and suggest discussing ACP during specific milestones such as with each hospitalization, change in health status or device implantation (Allen et al., 2012). Participating in ACP has been associated with increased quality of life, fewer acute care admissions, lower rates of depression and anxiety in caregivers and lower healthcare costs at the EOL (Dixon, Matosevic & Knapp, 2015; Detering, Hancock, Reade & Silvester, 2010; Zhang et al., 2009). Increasing ACP engagement for HF patients could lead to decreased rates of hospital admission, decreased stress and anxiety, improved patient-

provider communication and increased patient and family satisfaction with EOL care (Teno, Gruneir, Schwartz, Nanda & Wetle, 2007; Houben, Spruit, Groenen, Wouters & Janssen, 2014). Currently, the majority (76%) of HF patients do not participate in ACP, despite educational interventions and clinical guideline recommendations (Habal, Micevski, Greenwood, Delgado, & Ross, 2011; Evangelista et al., 2012). A discussion of common barriers to this practice will be provided in Chapter 3, however, one aspect that is not often addressed in the research is the fact that ACP is still commonly perceived as an individual process and provided using an individualized model of care (Sudore & Freid, 2010; Singer et al., 1998). There is evidence to suggest that this model is incongruent with the realities of the ACP experience, leading to low rates of participation, however this requires further examination (Singer et al., 1998; Robinson, 2012; Killackey, Peter, MacIver & Mohammed, 2019a).

A significant amount of ACP research has taken place within the oncology setting, and a recent review by Johnson, Butow, Kerridge & Tattersall (2016) suggested that standardized ACP practices do not sufficiently account for the complex social and emotional environments within which EOL planning takes place. Current conceptualizations of ACP, based in individualism and the right to self-determination, may misrepresent the way that ACP actually occurs for patients and family members: as a social process that takes place within the context of personal relationships. Limitations regarding reliable prognostication, unpredictable illness trajectories, high levels of complex device usage and limited patient and family understanding of cardiac disease are all challenges specific to the cardiovascular population and influence the ACP process. Therefore, further study of the social nature of ACP experiences unique to the cardiovascular setting is warranted.

In conclusion, ACP was formerly seen as a way for people to exert and preserve their individual autonomy by communicating preferences for future care in advance of incapacity (Davison & Torgunrud, 2007). In this model, participating in ACP has been equated with having documentation of an AD, demonstrating how ACP is embedded within a traditional biomedical approach to bioethics that is primarily concerned with the legalities of consent. There are significant limitations with equating ACP with documentation, which will be explored in further detail later in this thesis. However, in recent years there has been a shift in how we understand



ACP from being a document-driven practice focused on specific treatment decision making, to a process that involves communication regarding personal goals, values and preferences. Despite this conceptual shift, both research and clinical practice continue to focus on the role of formal medico-legal documentation in the process of ACP, and ACP continues to be provided in an individualized manner. There remains very limited patient engagement and low ACP participation rates in patients with HF; only one quarter of HF patients participate in ACP despite clinical guideline recommendations, public awareness campaigns and over 30 years of research and intervention development (Habal et al., 2011; Fried et al., 2006). This highlights the need for further understanding of how patients, families and healthcare providers view, understand and approach the practice of ACP in relation to their experience of autonomy.

### 3 Research questions

This study was guided by three research questions. The first two research questions were:

1. *How do people living with heart failure understand advance care planning?*
2. *How do people living with heart failure express autonomy when participating in advance care planning?*

Building on these questions, the third research question was:

3. *How does social location mediate heart failure patients' experience of autonomy and participation in advance care planning?*

In this study, I critically explored the experience and expression of autonomy in advanced HF and examined the influence of social location on the ability of people to participate in this complex social process. Research suggests that ACP is often enacted as a process of negotiating values and meaning throughout the trajectory of an illness in order to maintain social identities and relationships (Johnson et al., 2016; Robinson, 2011; Singer et al., 1998). Drawing on the conceptualization of relational autonomy developed by McLeod and Sherwin 2000; Sherwin, 1992; Sherwin, 1996a; Sherwin, 1998; Sherwin, 2000; Sherwin & Winsby, 2011, which views autonomy as a dynamic capacity shaped by social context, I explored what we can understand about the experience of ACP using this alternative model that is rooted in relationships as opposed to traditional individualism. I was specifically interested in the role of social location, and how this influenced the availability of meaningful opportunities to develop autonomy skills.

There is a long tradition of case-study methodology being used in the social sciences in order to explore, describe or explain a phenomena or social process and provide holistic and contextualized understandings (Baxter & Jack, 2008; Yin, 2009). Qualitative case study methodology served the purposes of my research for two main reasons. Firstly, understanding the social context is necessary for developing a comprehensive understanding of a particular phenomenon (Yin, 2009) and the goal of this study was to provide a broader examination of social forces that shape the experience of ACP for HF patients. In general, case study research seeks to answer ‘why’ and ‘how’ questions and allows researchers to develop a richer and more focused understanding than what is already known in an existing body of knowledge (Dooley, 2002). ACP research has been taking place for over 30 years without producing significant uptake or improvement in participation rates (Habal et al., 2011). By using a critical perspective to highlight relationships of power and taken for granted assumptions (Kincheloe & McLaren, 2005) and employing case study approach (both of which will be discussed further in upcoming chapters), this work provides an in-depth understanding of the relational and social context of ACP which will build on the significant, yet largely positivist, extant literature.

## 4 Description of Chapters

In this section, I briefly describe the chapters that form this thesis. Chapter Two presents the theoretical framework, specifically critical theory and feminist bioethics, using the work of McLeod and Sherwin, 2000; Sherwin, 1992; Sherwin, 1996a; Sherwin, 1998; Sherwin, 2000; Sherwin & Winsby, 2011; and Morgan, 1998 to examine concepts such as relational autonomy, social location and medicalization. Chapter Three situates the goals of this study within current and previous research that explores ACP in the context of cardiovascular disease, as well as literature that explores ACP in conjunction with relational conceptualizations of autonomy. Chapter Four outlines the methodological approach of this study, critical qualitative case study, and describes how relational autonomy was used as an analytical lens. Chapters Five, Six, Seven and Eight outline the findings of this study. Chapter Nine discusses these key findings and contextualizes the results within the current landscape of ACP literature. Chapter Ten outlines the conclusion and highlights the implications of this work, along with directions for future research. References and appendices conclude this thesis.

## Chapter 2

### Theoretical and Conceptual Framework

In this chapter I describe the theory and conceptual framework for this study. This chapter is organized into four sections. First, I begin by introducing feminist ethical theory and locating this theoretical perspective within the broader perspective of critical social theory. The epistemology and ontology of feminist ethical theory will be examined in relation to the population being studied. In the second section I discuss the relationship between neoliberal ideologies and the dominance of individual conceptions of autonomy. I then contrast this with the concept of relational autonomy put forth by feminist philosophers and differentiate between various models of relational autonomy in order to describe the conceptual approach that best suits this study. In the third section I explore key concepts such as social location and their relation to autonomy. Finally, I conclude with a justification for the use of feminist ethical theory and relational autonomy as a framework to achieve the aims of this research. I outline the rationale for employing feminist ethical theory to guide the study and, specifically, the conceptualization of relational autonomy developed by McLeod and Sherwin, 2000; Sherwin, 1992; Sherwin, 1996a; Sherwin, 1998; Sherwin, 2000; Sherwin & Winsby, 2011, as a suitable guide to study the experience of autonomy in EOL decision making within the context of chronic disease.

## 5 Introduction to Feminist Ethical Theory and Critical Social Theory

### 5.1 Critical Social Theory

Feminist ethical theory falls under the broader theoretical perspective of critical social theory. Critical theory holds the view that all thought and experiences are mediated by power relations, that certain groups in any society are more privileged than others, and that oppression is reproduced when subordinates accept their social status as normal, necessary or inevitable (Kincheloe & McLaren, 2005). In alignment with feminist ethical theory, this perspective also dictates that social structures shape and represent reality, that power relations define reality, and

that people have agency and potential for autonomy despite the existence of potentially oppressive social structures (Kincheloe & McLaren, 2005).

Critical theory was chosen to guide this study for five key reasons. Firstly, critical theory can help identify different ways of defining the specific problem being studied (Denzin, 2015). This is because using critical methods allows for a variety of perspectives to be compared and contrasted in order to reorient a problem that may be challenging to solve (Denzin, 2015). As will be discussed in the literature review, this is an especially important part of this thesis because ACP has existed as a healthcare practice for over 30 years, yet still poses a challenge to both patients and healthcare providers alike in terms of participation and uptake. Moreover, the current construction of ACP reflects societal power relationships, specifically related to the dominance of biomedicine, with a focus on individual autonomy and legalistic understanding of ethics. Various perspectives on this social process are needed in order to provide a comprehensive view of the state of ACP practices and their suitability as a means to support patient autonomy.

Secondly, critical theory allows existing assumptions that are held by a variety of stakeholders to be clearly identified and examined in order to illuminate “correct” or “incorrect” assumptions (Denzin, 2015; Kincheloe & McLaren, 2002). This process of illuminating existing assumptions was initiated through the literature review process, which outlines a number of assumptions under which ACP research is currently being conducted. Thirdly, critical theory allows for the identification of aspects of social life or social processes that can support the development of future intervention (Denzin, 2015). Since the inception of this work, one of the overall goals has been to explore ACP using an alternative framework and identify new areas for potential future intervention in order to enhance the autonomy of those living with chronic illnesses. Fourthly, and most importantly for this study, critical theory supports the interpretation and assessment of a problem from alternative moral perspectives (Denzin, 2015). The benefits of using relational autonomy as an alternative moral perspective from which to frame the ACP process, and using critical theory supports this objective. Fifthly, using critical theory can highlight the limitations of quantitative evaluations and supports the use of qualitative and interpretive methods (Denzin, 2015). Again, this will be highlighted through the literature review, which outlines how current

quantitative measures of ACP participation and uptake do not align with the most recent conceptualizations of the process and fail to provide insight into the contextual, interpersonal and emotional challenges that patients have when participating in the ACP process.

In conclusion, this study was guided by a critical social theory with the goal of examining social forces that shape the experience of patients participating in ACP, in hopes of identifying new areas for interventions and empowering patients making EOL care decisions. The following section will provide an overview of feminist theory and feminist bioethics as they relate to this study.

## 5.2 Feminist Theory

Feminist ethical theory is derived from the political viewpoint of feminism, which holds the oppression of women as both morally and politically wrong and seeks to provide a critical analysis of forces that shape systemic oppression (Sherwin, 1989a). This perspective allows for social forces such as gender, class, race, sexual orientation, social location, relationships and responsibilities to be analyzed, with the goal of eliminating or ameliorating the oppression of any group of people (Tong & Williams, 2009). Based on this goal, an important aspect of feminist theory is conceptualizing the role of power as an influential force when making sense of experiences, and exploring how power is implicated in the production of knowledge (Ramazanoglu & Holland, 2002).

Despite the overarching focus on oppression and power, feminist theories have drawn on a variety of conceptualizations of power and therefore do not hold a unified theory of power (Ramazanoglu & Holland, 2002). However, feminist theory generally uses a normative framework that interrelates injustice, politics, and ethical practices that eschew the unjust exercise of power (Ramazanoglu & Holland, 2002). This perspective also aligns with an emancipatory approach, which seeks to identify and confront various sources of social oppression (Lincoln & Guba, 2000). Importantly for this thesis, studies do not have to be limited to exploring the experiences of women in order to qualify as feminist work. Projects are feminist if they are framed by feminist theory and aim to produce knowledge that will be useful for the transformation of injustice and subordination. In this case, the project is framed by feminist

ethical theory and seeks to identify systems of oppression or constraint that hinder the enactment of personal autonomy through the ACP process and, therefore, this qualifies as feminist work using an emancipatory approach (Ramazanoglu & Holland, 2002).

The epistemological and ontological perspective of feminist theory is centered on the concept of situated knowledge (Code, 1991; Grasswick, 2013). Situated knowledge dictates that both what is considered to be knowledge, as well as the method of knowledge production, reflect the situation or perspective of the knower (Code, 1991; Grasswick, 2013). Knowledge is frequently characterized as local and limited, and research using this perspective is interested in exploring how agents actively engage in practices of knowing, especially within systems of oppression (Code, 1991; Grasswick, 2013). Finally, feminists are frequently opposed to the traditional view of subject/object dichotomy (Code, 1991; Grasswick, 2013). Instead, theorists look to develop socially informed conceptions of objectivity, and prefer to define “objective” in the sense that experiences can be translatable across particular subjective locations (Code, 1991; Grasswick, 2013). This is especially important in this thesis as I explored the experiences of a small group of people, but seek ways of translating these findings to other groups who may encounter similar constraints. This will be discussed further in Chapter 4 in relation to the transferability and trustworthiness of the results of this study.

### 5.3 Feminist Ethical Theory

Mainstream ethical theory is frequently described as employing abstract principles, such as justice, beneficence and autonomy, to decontextualized conflicts or dilemmas in order to analyze challenging ethical questions. It has been suggested that these bioethical principles have been developed based on typically masculine ideals of morality, such as the importance of individual rights and freedoms, and therefore tend to be reductive and lack an examination of relevant contextual features and social forces. In the late 1970s and early 1980s, Gilligan (1982) began to question this dominant framework of morality, because it tended to view women as less morally developed than men (Lindemann, 2006). When Gilligan (1982) studied the moral decision making of women, she noted that when analyzing ethical dilemmas, women focused on the relationships established between people and viewed themselves as connected to others as opposed to individual, autonomous agents. Women incorporated concepts such as

interconnectedness, vulnerability, dependence, and trust to analyze ethical dilemmas and explored relationships of responsibility and care (Gilligan, 1982). This approach to ethical deliberation was coined the ‘ethic of care’ and highlighted women’s moral experience that prioritized caring for others over following generalizable rules or principles such as justice and fairness (Gilligan, 1982; Sherwin, 1989b).

Following Gilligan’s work, the ethic of care was further developed by authors such as Noddings (1984), Baier (1987), Held (1993; 2006), Tronto (1994; 2005), and others. The major themes that developed in this scholarship focused on care of the self and others, alleviation of suffering, the maintenance and restoration of relationships and a focus on the primacy of the situation or context over the primacy of abstract principles (Peter & Liaschenko, 2006). An ethic of care was also criticized for a number of reasons, most importantly due to its lack attention to social justice (Lindemann, 2006; Peter & Liaschenko, 2006). Lindemann (2006) argued that the ethic of care does not have the scope to examine broader social problems due to its focus on individual relationships, and that there is a responsibility to explore social inequalities (Peter & Liaschenko, 2006). However, more recently, because some formulations of an ethic of care have been developed to incorporate social justice, or the understanding that privileges and burdens should be equally distributed across society (Miller, 2017), there can be very little difference between feminist ethical theory and an ethic of care specifically. The following sections will discuss the similarities between an ethic of care and feminist ethical theory, and provide a brief overview of feminist bioethics specifically.

## 5.4 Feminist Ethical Theory and Ethics of Care

Feminist ethical theory and ethics of care have a number of common features. Firstly, they both highlight the moral significance of the practices and values of women, such as nurturance, protection, subjective knowledge and attentiveness (Peter & Liaschenko, 2006). Secondly, both view people as interdependent, vulnerable, and differentially situated based on unique intersections of gender, race, culture, economics, history and politics; this outlines a relational approach to autonomy, which will be explored further (Peter & Liaschenko, 2006). Thirdly, there is a strong focus on everyday life and experiences, and an understanding of morality as negotiations of responsibility (Walker, 2003; Peter & Liaschenko, 2006). Fourthly, feminist

ethics provides a critique of moral and epistemic privilege and highlights the subjective knowledge of the situated individual as central by noting that morality exists in practices and relationships (Walker, 2003; Peter & Liaschenko, 2006; Simmonds, 2008). Feminist ethics therefore argues that ethical theory must be relevant to daily life by integrating ethical theory and moral experience (Walker, 2003; Peter & Liaschenko, 2006). Finally, there is attention to power, oppression and social justice using an intersectional lens that seeks to examine the way power shapes relationships with the goal of transforming existing oppressive relationships (Peter & Liaschenko, 2006).

## 5.5 Feminist Ethics of Care and the Neoliberal Critique

As mentioned, feminist philosophers challenge the neoliberal notion of the self, which suggests that individuals are independent and self-interested rational actors, and reject these assumptions as problematic and inaccurate (Parekh & Wilcox, 2018) because these assumptions suggest that human relationships are formed by choice as opposed to relationships of necessity, dependency or vulnerability (Parekh & Wilcox, 2018). Neoliberalism prioritizes individualism and independence over other values, such as equality and care, and overemphasizes concepts such as self-management, without acknowledging that many illnesses cannot be managed by an individual alone (Parekh & Wilcox, 2018). Robinson (2011) describes this as neoliberalism's "blindness to interdependence, vulnerability and the public role for caring practices" (p. 79). Many feminists critique the tenets of neoliberal discourse by challenging the assumption of individualism and continuing to insist that agency should not be equated with autonomy, and, therefore, put forth relational accounts of agency and autonomy to support this sentiment (McAfee & Howard, 2018).

A feminist ethic of care challenges both neoliberal assertions and traditional moral theory that is dominated by an emphasis on the rational, self-interested individual (Peter & Liaschenko, 2014; Parekh & Wilcox, 2018). Proponents of feminist ethics purport that human beings are fundamentally relational, interdependent, and defined by caring relationships, and society relies on relationships to function (Parekh & Wilcox, 2018; Tronto, 2015). Every person relies on the care of others in order to survive, and therefore "vulnerability, dependency and need should be understood not as deficits or limitations," as they are under neoliberal assumptions, but rather



should be viewed as essential human qualities and universal experiences (Parekh & Wilcox, 2018). Feminist ethicists realize that power relations cannot be separated from practices of caring, and that caregivers are generally in positions of power in relation to those they are caring for (Tronto, 2015).

Tronto (2015) also notes that the overall effect of market-focused policies and neoliberal democracies that primarily emphasize economic growth result in inequality and create an “uncaring hierarchy” (p. 25) among citizens. This effect allows some people to be seen as participating citizens (independent, rational actors able to be economically successful) and some to be excluded from this view (people who may be dependant and vulnerable such as children and older adults). As mentioned, the ideals of neoliberalism reflect the interests of the most privileged in society and therefore do not align with an understanding of people as vulnerable and interdependent (Peter & Liaschenko, 2014). This perspective further complicates the process of ACP, which is specifically designed as a practice to support the autonomy of those who may experience dependency and vulnerability in the future.

The role of neoliberal discourse in the provision of healthcare and its strong focus on individual autonomy, self-direction and self-management will be incorporated into the analysis of the data by acknowledging the ways this social force may shape the experience of autonomy and ACP. Furthermore, including an understanding of neoliberalism within this research will guide the theoretical analysis of concepts such as individualism and independence, and allow for the development of an understanding of ACP that moves beyond personal behaviour and acknowledges the role of historical and political contexts.

## 5.6 Feminist Bioethics

Feminist bioethics falls within the critical social paradigm and is the theoretical approach being used in this study. Feminist bioethics developed within philosophical thought (as opposed to sociological thought) as an alternative to the principle-based approach of traditional bioethics, which is the ethical framework most commonly employed in the healthcare setting (Sherwin, 1992). Feminist ethical theory brings attention to the social location of moral agents in general with an explicit focus on vulnerable and oppressed groups (Sherwin, 1992; McLeod, 2002;

MacKenzie & Stoljar, 2000; Mackenzie, Rogers & Dodds, 2013), but, as opposed to mainstream feminist theory, does not necessarily prioritize gender over other social factors (Dodds, 2000). In this sense it has been suggested that “feminist” ethics is more akin to “critical” ethics (Robinson, 1997; Wise, 1995), however there has not been substantial literature developed to support this shift in terminology.

The power of biomedicine and medicalization as a dominant social force and the individualistic model it adopts will be explored as a potential source of constraint for patients and families. In terms of gender, Dodds (2000) has noted that the inadequacies of the dominant (or biomedical) conception of individualistic autonomy apply to any person who is in need of healthcare, not only to women. As discussed previously, this individualized model equates autonomy with informed consent using the ‘voluntary choice model,’ yet considering patients are often not in a position to make a voluntary choice regarding their illness experience this model is inadequate when conceptualizing the experience of autonomy for patients seeking medical care (Dodds, 2000). Therefore, this study is not restricted to exploring the experiences of women, however it will include an analysis of gender roles and how societal norms and experiences of dependence and vulnerability that accompany being ill may influence the ACP experience.

Feminist bioethics is based on a conceptualization of morality that prioritizes social roles and responsibilities and is rooted in the examination of contextual detail, as opposed to focusing on abstract reasoning (Sherwin, 1989b). Overall, feminist bioethics is distinguished from other ethical theories by suggesting that moral and social practices are inseparable, and holds a primary commitment to identifying, exploring and ideally improving the social conditions that lead to systematic oppression of certain groups (Peter & Liaschenko, 2006; Sherwin, 1989b). Feminist bioethics challenges the assumption that health decision making is apolitical and asocial and suggests that persons are best understood as social and relational moral agents (Dodds, 2000). Importantly for this thesis, feminist bioethics is not only focused on oppression, but is equally interested in exploring the possibilities for agency that can be found within groups that are constrained (Sherwin, 1992). The goal of improving agency is especially relevant for this project, because by examining the structures that enhance or reduce an individual’s ability to exert their autonomy through ACP, this work will illuminate hidden or unexamined power

relations with the goal of reducing constraints and enhancing conditions that promote moral agency.

## 6 Autonomy

According to Beauchamp & Childress (2001), the word “autonomy” is derived from the Greek language and originally referred to the ability of city-states to independently self-govern. The principle of individual autonomy is rooted historically in the liberal traditions of the Enlightenment era in Europe, where the central themes of individual liberty, rights and freedoms were dominant forces in shaping the ethical justification of personal action (Azetsop & Rennie, 2010). Although there are many theories of autonomy, each of which requires different conditions to be upheld by the acting agent, all theories have two components in common: liberty, or freedom from controlling influence, and agency, or the presence of capacity for individual action (Azetsop & Rennie, 2010; Beauchamp & Childress, 2001; Beauchamp, 2016).

Dworkin (1981), a renowned autonomy theorist, originally suggested that autonomy is used in different ways by different authors, and is presented in an increasingly broad fashion, which continues to be true today. In his perspective, autonomy was frequently equated to liberty, self-rule, sovereignty, dignity, integrity, individuality, freedom of the will, self-assertion, freedom from obligation, and a thorough knowledge of an agent’s own desires, values or interests (Dworkin, 1981). Overall, Dworkin (1981) defined autonomy as one’s ability to identify their values, goals, desires, and the influences that motivate them to act. Since then, the concept of autonomy in bioethics has been both deeply contested and well developed. An overview of both individual and relational accounts of autonomy will be provided.

### 6.1 Individual Autonomy

Beauchamp & Childress have developed a universal framework of principles that has been widely used in healthcare over the past 40 years (Beauchamp & Childress, 2001; Beauchamp, 2016). Beauchamp (2016) provides a practical bioethical definition of personal autonomy as “self-rule free of controlling interferences by others” (p. 5). This approach to autonomy includes both a positive and negative obligation. Positive obligations include “respectful and appropriate information exchanges and actions that foster and encourage autonomy” (Beauchamp, 2016 p.

5). Negative obligations require that autonomous actions “not be subjected to controlling constraints by others” (Beauchamp, 2016 p. 5). Overall, the dominant approach to autonomy has been shaped by this principlistic view, which is centered on the concept of individualism.

The principle of respect for individual autonomy has been foundational in the structure and function of healthcare systems, specifically in terms of policy and program development, practice guidelines and documentation requirements. Most notably, the requirement to respect autonomy translates into the healthcare provider’s requirement to secure an agent’s voluntary and informed consent for all treatments and procedures (Beauchamp 2016; Stoljar, 2011).

## 6.2 Informed Consent

Informed consent (IC) is the dominant method used to secure autonomy within current healthcare systems. In alignment with both the positive and negative obligations required for autonomous action, informed consent can be defined in two parts. Firstly, IC supports autonomy by ensuring full disclosure of information to a competent patient who fully understands all that has been disclosed, which fulfills the positive obligation of information provision (Stoljar, 2011; Beauchamp, 2016). Secondly, IC requires the patient to voluntarily consent to treatment, free from coercion, interference or controlling influence which fulfills the negative obligations of autonomous action (Stoljar, 2011; Beauchamp, 2016). Stoljar (2011) simplified this conceptualization by identifying the conditions that are understood as necessary and sufficient for securing patient autonomy in the healthcare setting: information provision combined with a stance of non-interference by the clinician. As most practicing clinicians will be aware, this process is rarely so simplistic; the application of the doctrine of IC is fraught with tensions involving the scope and depth of information provision, ensuring understanding of the information, conflict regarding capacity to consent, role of family members and healthcare providers in decision making, challenges with documentation and more.

Some scholars critique the ideal of autonomy as it is portrayed in the process of IC, primarily because it treats all people as interchangeable and does not align with the experience of those living within complex relationships and with social responsibilities (Sherwin & Winsby, 2010). This conceptualization is especially incongruent with the experiences of those who are ill, trying

to navigate a complex healthcare system, vulnerable, in pain, or dependent on the care of others (Sherwin & Winsby, 2010). The idea that patients can “draw upon all the resources necessary, deliberate objectively, arrive at independent judgments and communicate their decisions effectively” does not accurately reflect the experiences of situated moral agents (Sherwin & Winsby, 2010, p. 184). Additionally, the dominant view of IC has been criticized for ignoring the contextual differences between patients, and focusing too heavily on evaluating the competency of patients while ignoring the range of alternative options that may actually be available to people (Sherwin & Winsby, 2010, p. 184).

An additional example of the practical application of the concept of autonomy is found in the more recently developed process of ACP. ACP has been developed under the model of IC. This practice encourages clinicians to provide relevant clinical information to patients, and encourages patients to discuss personal values and healthcare goals and document these views in advance, in order to guide the care they receive during periods of incapacity or at the EOL (McMahan, Knight, Fried & Sudore, 2013; Singer et al., 1998). Again, although this practice has the goal of supporting and upholding individual autonomy, ACP has not achieved its originally expected level of public uptake and remains a practice fraught with challenges at the implementation level (Singer et al., 1998; McMahan et al., 2013).

Overall, feminist philosophers have viewed the dominant assumption that autonomy is inherent in the IC process as problematic. Positioning respect for autonomy within the informed consent process presupposes that ethical concern should be directed to the information giving and non-interfering actions of the clinician who is obtaining consent, instead of focusing on supporting the decision making process of the patient (Stoljar, 2011; Sherwin & Winsby, 2010). This assumption may have allowed for minimal and shallow information-giving behaviours to become the moral norm for clinicians and continues to pass as fulfillment of this complex principle (Sherwin & Winsby, 2010). As an example, the routinized and often rushed procedure of signing a consent form prior to same-day cardiovascular procedures such as PCIs prioritizes the legality of informed consent and documentation as over the informational and decisional support needs of the patient. Focusing on informed consent also ignores the ways in which health care practices influence the development or demise of personal capacities for autonomy

(Meyer, 1989; Stoljar, 2011; Sherwin & Winsby, 2010). Many argue that there is still a significant level of medical paternalism that takes place throughout the process of informed consent, as it is left to practitioners to decide what information is relevant to each patient based on subjective assessments; therefore, these professionals act as the gatekeepers of important health information (Meyer, 1989; Dodds, 2000; Sherwin & Winsby, 2010). Practices such as gatekeeping may actually reduce opportunities to develop capacities that are necessary to exercise personal autonomy, as choices are often limited by social factors and there is not always freedom to exercise careful consideration and reflection within the time-constrained structure of the healthcare system (Meyers, 1989; Dodds, 2000).

It is clear that the processes of individualized IC and ACP may not truly support patient autonomy for all (or even most) patients in the healthcare system, especially in a multi-cultural context such as Canada; therefore, relational conceptions of autonomy will be explored in the next section as an alternative.

### 6.3 Relational Autonomy

Relational autonomy is the name for a cluster of approaches to autonomy that emphasize the socially embedded nature of agents (Sherwin & Winsby, 2010). This approach attends to the social, political and economic conditions that influence the identities and decision making of moral agents and considers the embodied social location and experience of people (Sherwin & Winsby, 2010). Relational autonomy can be understood as the recognition that self-governance is both defined and pursued in a social context, and that this context influences the opportunities an agent has to express or develop autonomy skills (MacLeod & Sherwin, 2000). Relational autonomy also seeks to identify the ways in which the ability to be self-directed is affected by social and political forces and rejects the idea that autonomy is an achievement of individuals (MacLeod & Sherwin, 2000).

Relational autonomy conceptualizes moral agents as people with historical roots, who develop within specific contexts and shape their identity through relationships with others (Sherwin, 1992). Individuals learn moral values, judgements and behaviours through relationships and responsibilities within communities, and identities are configured through both interpersonal and

political relationships (Sherwin, 1992; Sherwin, 1998; Simmonds, 2008). Each agent's particular social location is influential in establishing priorities, concerns, values and beliefs (Sherwin & Winsby, 2010). Social location also determines what types of opportunities are available to different agents to support their development of autonomy skills (Sherwin & Winsby, 2010). By incorporating social and political relationships as well as power dynamics, this conceptualization of autonomy recognizes the presence of constraining forces and provides an exploration of how these factors may interfere with one's ability to exercise autonomy by undermining one's sense of self (Sherwin, 1998). In general, this perspective is particularly concerned with social justice and considers the impact of patterns of inequality and prejudice on the options and opportunities available to people (Sherwin & Winsby, 2010).

### 6.3.1 Trust and Self-Trust in Relational Autonomy

Patients navigating the healthcare system are often required to trust both the institution and the healthcare providers who work within it, because they may experience a lack of control over their illness, they are vulnerable when they are ill and are often placed in social situations that limit their options (Dodds, 2000). While patients may occasionally have the ability to choose where or when they seek medical care, the healthcare encounter is largely outside of the patient's control. Choices are often limited in the healthcare setting, and options available to each patient differ based on social, physical and economic location. Patients are obligated to trust their providers as they decide what information and treatment options are relevant to each patient. This requirement for trust and heavy reliance on healthcare professionals is an example of the relational power dynamics that pervade the healthcare setting. As Christman (2014) notes, relational dynamics are especially important to consider when the potential paternalist (i.e. a HCP) and the subject of paternalism (i.e. a patient) occupy different social locations, have asymmetries in power and have different cultures, races and language; this describes a significant portion of patient-provider relationships in the Canadian healthcare context.

These power dynamics are relevant in any healthcare situation, but are especially important to consider when examining the process of ACP. The target population for ACP is primarily older adults and the acutely or chronically ill, but ACP is also campaigned as a process that is pertinent to any healthy member of the general public in order to ensure that personal healthcare wishes

are followed. Beyond the extreme vulnerability of the target population, the general public is also very uninformed on the nature of most disease trajectories, the availability of possible interventions and potential outcomes. They may also have limited experience making medical decisions and underdeveloped self-trust and self-esteem in the context of decision making. Additionally, vulnerable individuals may not have all the information or the capacities to exert self-direction without some assistance or decision making support.

Overall, this consideration of self-trust as an autonomy competency reflects the reality discussed by Stoljar (2011), in which having negative freedom, or freedom from external obstacles or impediments, is vastly different than having positive freedom, or the freedom to act according to choice and exercise control. Therefore, when considering the process of ACP, a thicker conception of autonomy is necessary, which utilizes a relational approach to capture the ideas of positive freedom, social identities and encourages strong evaluation with an explicit focus on the promotion of self-trust as an autonomy-enhancing competency.

The current process of ACP, which rests on individualistic accounts of autonomy, relies heavily on the idea that all patients have an adequate autonomy competencies and sufficient experience making healthcare decisions, and therefore have the ability to decide what kind of treatment and care they may want. This process also assumes that patients are able to fully access these autonomy competencies when making challenging decisions regarding future care as well as decisions regarding death and dying. As Johnson et al. (2016) note, the notion that ACP is concerned primarily with the patient's right to self-determination through control over treatment choices at the EOL may misrepresent the way that these decisions are made and conflict with the actual needs of patients, who experience ACP as a relational, emotional, and social process. In this dissertation, I will explore this experience for patients and contribute to the development of a relational model of ACP in HF management.

## 7 Key Concepts

Throughout this chapter, many important theoretical concepts have been discussed and examined in relation to this research. The following key concepts have been foregrounded as especially



relevant to the research questions and were explicitly employed to support the data generation and analysis process. These key concepts are defined as follows:

## 7.1 Relational Autonomy

Relational autonomy is a cluster of approaches to autonomy that emphasize the socially embedded nature of agents (Sherwin, 1998; McLeod & Sherwin, 2000; Sherwin, 1992). This account of autonomy views the ability to be self-directed as influenced by social and political forces and highlights the fact that the self exists fundamentally in relation to others (Sherwin, 1998; McLeod & Sherwin, 2000). Overall this approach understands agents' identities to be formed within the context of social relationships and shaped by complex intersecting social determinants (McLeod & Sherwin, 2000). Based on this, autonomy is best understood as a set of capacities or skills that are developed (and constrained) by social circumstances (Meyer, 1989; Sherwin, 1989). Importantly, this approach recognizes that social location determines what types of opportunities are available to different agents to support the development of autonomy skills, and therefore it is necessary to incorporate an exploration of social location in order to understand a person's ability to exercise autonomy (McLeod & Sherwin, 2000).

## 7.2 Social Location

Social location consists of ascribed social identities (i.e. gender, race, sexual orientation, ethnicity, kinship status), and social roles and relationships (i.e. occupation, political party membership, familial positioning, etc.) (Grasswick, 2013). Oppression, or constraint, is a component of social location and is the result of intersecting power relationships or forces that immobilize or reduce a group or category of people (Sherwin, 1992). Generally these constraints are part of a broader system that asymmetrically and unjustly disadvantages one group and benefits another (Sherwin, 1992). Social location is a key component of relational autonomy, as it takes into account the impact of social and political structures, especially sexism and other forms of oppression, and examines how they influence the lives and opportunities of people (McLeod & Sherwin, 2000). Many intersecting forces of oppression shape society, and agents experience these forces in unique and distinct ways as each person belongs to multiple groups with multiple locations (McLeod & Sherwin, 2000). This means that one may be privileged in some respects and oppressed in others, and this type of complex positioning has an impact on the

agent's opportunities to develop the skills necessary to act autonomously (McLeod & Sherwin, 2000). Circumstances that support the development of these skills are not only produced by broad social forces but are also the product of individual interpersonal relationships; therefore, social location incorporates a person's unique positioning within multiple social groups as well as within personal relationships (McLeod & Sherwin, 2000).

## 7.3 Medicalization

Medicalization is the unintentional or intentional expansion of the domain of medical jurisdiction, where successful medicalization involves individuals, groups and cultural institutions viewing (or coming to view) a domain, problem, condition, choice or life circumstance in medical terms (Morgan, 1998). Medicalization involves shared cultural practices that support the legitimacy of using medical concepts, theories and discourses to describe normal life phenomena (i.e. birth and death) and accepting the use of medical interventions to “treat” these conditions (Morgan, 1998). Bioethics mirrors biomedicine's consistent tendency to approach illness as primarily a problem of individuals (Sherwin, 1998). Within the biomedical model, suffering is located and addressed in the individuals who experience it rather than attributed to the social arrangements that may be responsible for causing the problem, and therefore healthcare providers generally respond to the symptoms troubling particular patients in isolation from the context that produces these conditions (Sherwin, 1998). Recently, due to the secularization of society and the rise of healthcare professionalism, the aim of healthcare has come to be understood as that of restoring health and prolonging life (van Heijst, 2009). The primacy of postponing death above all else, and the value of prolonging life seems self-evident to many healthcare providers, who consider it the primary means of measuring good care (van Heijst, 2009). Overall, medicalization can be understood as a complex process that involves pervasive aspects of social control, which are justified by the goals of preserving or restoring health and preventing disease (Morgan, 1998; Purdy, 2001).

## 8 Justification of Theory and Key Concepts

Feminist ethical theory was used to guide this study because it supports a relational conception of autonomy. The concept of relational autonomy is one of the most important contributions

feminist ethics has provided to current moral philosophy. Currently, ACP is conceptualized as a practice rooted in individualism and rational thinking; this understanding fails to account for the influence of social location as well as emotional and relational forces on the ability of people to plan for the EOL. By employing feminist ethical theory, my inquiry and analysis not only included, but highlighted the influence of social location on the ability to exercise autonomy. This perspective aligns extremely well with relational autonomy as it acknowledges the role of socio-political forces that can enhance or suppress the development of autonomy, while also recognizing that autonomy is still possible for those who exist in constraining structures (i.e. patients within the healthcare system).

Finally, employing the key concept of social location is especially characteristic of feminist theory. In the case of my research, I suggest that illness makes patients dependent on the care of others and may reduce their ability to exercise autonomy the way it is traditionally considered, leaving them vulnerable to idealistic and individualistic conceptualizations of autonomy that may be unachievable. Empirical studies of empowerment and choice in chronic illness have demonstrated that while empowerment language is frequently observed in the neoliberal healthcare setting, the behaviour of healthcare providers implies continued professional dominance (Paterson, 2001). Through tactics such as discounting experiential knowledge and failing to provide adequate resource for informed decision making, healthcare providers have covert and subtle ways that they contradict their stated goal of empowerment and equal participation when working with patients with chronic illness (Paterson, 2001). In general, dominant social forces such as the power of biomedicine and the discourse of medicalization can inhibit self-confidence at the various levels of autonomous decision making (McLeod, 2002) and if one is systematically denied acknowledgement as a knower and credibility is withheld, then one's agency can be diminished (Code, 1991).

Using these concepts has also allowed for the identification of opportunities for empowerment within the context of chronic disease management and EOL planning. As discussed by Singer et al., (1998), relationships and responsibilities are of utmost importance to those participating in ACP, and this perspective captures the complex emotional and social processes that take place during this process. Methodologically, feminist ethics grounds theory in the daily experiences of

moral agents using qualitative social scientific methods (Sherwin, 1998). This allows the researcher to capture empirical information about the situated encounter with medicine and healthcare and gain insight into the experience of patients and the multiple influences that shape daily decision making practices (Sherwin, 1998a).

Overall, feminist ethics was best suited to guide this exploration because it seeks to highlight oppressive forces within moral and ethical healthcare practices, but is equally interested in establishing opportunities to improve or enhance individual agency, despite potential or actual constraint (Sherwin, 1989a). The goal of this thesis was to explore the experiences of ACP for patients and families living with HF and identify opportunities to enhance their autonomy through this social process. Additionally, as there are currently no studies that employ feminist ethics to examine the experience of ACP for people living with HF, this study contributes theoretical understanding to this evolving issue.

## Chapter 3

# Advance Care Planning in Heart Failure: A Narrative Review of the Perspectives and Experiences of Patients, Families and Healthcare Providers

The overarching purpose of this review is to provide an examination of ACP in the HF population using the lens of relational autonomy. This provides an alternative perspective from which the current conceptualization of ACP, as a practice grounded in individualistic autonomy, can be juxtaposed. Overall, this review will highlight the relational nature of ACP as an inherently social process and provide a starting point from which to further explore ACP in the context of chronic disease management.

I will take the following format in this review: the methodology of the narrative review will be briefly described in addition to a discussion of database selection, final search results and inclusion and exclusion criteria. Following this, I will provide an overview and appraisal of studies included in the review in order to present a current understanding of the state of ACP within the HF population. A synthesis of relevant themes that demonstrate the relational nature of the ACP process will be provided. Following this, I will provide a brief overview of literature that incorporates a discussion of relational autonomy in conjunction with ACP. To conclude this chapter, I will offer suggestions for future work based on the results of this review.

## 9 Methodology

The finalized search strategy used for this review was developed with the support of an Information Specialist at the University Health Network's Toronto General Hospital. Based on the goal and content of the search, the following databases were used: CINAHL, MEDLINE, MEDLINE In Process, PsycINFO, Scopus and Sociological Abstracts. MeSH headings and keywords to identify the population were selected based on a heart failure search hedge developed at the University Health Network and the search was completed on June 20, 2016. MeSH headings related to advance care planning were selected based on recent systematic reviews examining this practice (Johnson et al., 2016). Examples of specific MeSH headings

(MH) and keywords (\*) include: advance care planning (MH), advance directive (MH), living will\*, power of attorney\*, substitute decision maker, patient/healthcare provider/family member experience\*, patient/family/healthcare provider perspective\*, heart failure (MH), ventricular dysfunction (MH), cardiac\* fail\*, heart decompensation\*.

In total, 1134 unique articles were identified; duplicates were removed, and articles were then reviewed by title and abstract for eligibility (See Table 1, Figure 1 and Appendix C for Search Results, Strategy Flow Chart and Eligibility Criteria). Articles were included if they met one of the two following criteria groups:

1. Studies examining ACP practices, implementation, interventions, prevalence, or awareness in the cardiovascular population
2. Studies examining the perspectives, experiences, or EOL preferences of patients with heart failure, their family members or their healthcare providers

Articles providing ethical or moral examinations of ACP were used for contextual development. 78 articles were selected for full-text review and 42 articles were included in the final synthesis of results (see Appendix E: Search Strategy Flowchart). Hand searching produced 10 unique articles; those that did not fit inclusion criteria were used for contextual development of the review. During the period of August 2019 to December 2019, I conducted a follow up literature search that employed the same electronic databases and keywords as the original search, but between the years 2016 to 2019. In order to review the literature on new topics uncovered since the first literature search related specifically to ACP in the context of HF, I incorporated new keywords into the search including: relational autonomy, goals of care, palliative care, consent, trust and decision making. These results have been integrated into the following review.

Data extracted from full-text review included research objectives, study design, population, methodology, findings, limitations, and future research suggestions. Quantitative studies were appraised using Critical Appraisal Skills Program (CASP) methodology and qualitative research was appraised using both CASP guidelines and Eakin and Mykhalovskiy's (2003) guidelines for qualitative research assessment (CASP Guidelines). This approach was chosen in order to avoid a proceduralistic evaluation of qualitative research, and instead focus on substantive

contributions by using individual study methods as a resource for understanding the respective study results (Eakin & Mykhalovskiy, 2003).

This was not a formal systematic review or meta-analysis and therefore studies were selected based on their ability to provide an overview of the key features of ACP within this population, with a focus on studies that provided perspectives on ACP as a social, emotional and relational process. This approach is consistent with the style of literature review being conducted; narrative reviews are best suited to presenting a broad perspective on a topic using theory and context and presenting philosophical perspectives in a balanced manner (Green, Johnson & Adams, 2001). In the case of this review, the narrative style works to highlight the juxtaposition between individualistic and relational accounts of autonomy in the context of ACP as a healthcare practice. Narrative reviews do not aim to provide aggregate data but instead seek to interpret current research by developing relevant themes and broadening understandings of a particular phenomenon; the phenomenon under exploration in this case is ACP and the way it is framed as an autonomy enhancing practice within the chronic illness context (Grant & Booth, 2009).

## 10 ACP in Heart Failure: Current Practices

### 10.1 Prevalence and Awareness of ACP in HF Patients

A number of studies have made efforts to examine the status of ACP in the HF population by proxy of surveying awareness and prevalence of advance directives. Advance directives (ADs) can be defined as the documentation component of ACP, and usually consists of one or both of the following documents:

1. A legally designated substitute decision maker (SDM); in Ontario this document is called a Power of Attorney for Personal Care (POAPC).
2. A written declaration of personal values, wishes, or specific treatments that the patient would accept or not accept when they are incompetent or unable to provide personal consent (often called a living will) (Tajouri, Ottenberg, Hayes, & Mueller, 2012; Tobler et al., 2012b).

Recent studies have suggested that there is a wide range of awareness and prevalence of ADs in the HF population. Most significantly, two Canadian studies demonstrated that only 24-44% of cardiovascular patients were aware of ADs (Habal et al., 2011; Tobler et al., 2012b). Dev et al., (2012) found that ACP was rarely discussed in HF management, HCP were often unaware of patients' preferences for resuscitation, and that ACP rarely included preferences regarding ICD use or deactivation (Dev et al., 2012; Gerlich et al., 2012; Kelemen, Ruiz & Groninger, 2016). More recently, Delmaczynska & Newham (2019) found that ACP is routinely underused in LVAD centres, despite the strong evidence recommending the importance of ACP completion in this population. These results can be quite region-specific, as studies done in regions with higher percentage of white patients or older average age of sample tend to display higher prevalence of ADs and on average, patients with an AD were more likely to be white and older in age than patients who did not have an AD (Tajouri et al., 2012; Pasalic, Tajouri, Ottenberg & Mueller, 2014). Overall, using ADs as a proxy outcome measure for exploring the success of the ACP process within the HF population demonstrates a significant lack of patient uptake and completion as well as low rates of overall awareness, despite current guidelines recommendations and efforts to improve participation.

## 10.2 ICD Deactivation

When examining the prevalence of ADs in patients with HF and those who specifically received cardiac devices, studies found that although a larger percentage (between 30-59% of patients surveyed) had ADs, ICD deactivation was rarely discussed (Dev et al., 2012; Tajouri et al., 2012; Pasalic et al., 2014). Habal et al. (2011) revealed that only 11% of patients who had ICDs were aware that their devices could be deactivated, and Tajouri et al. (2012) reported similar results in that only 2% of the ADs completed by patients with ICDs mentioned the device or its deactivation at the EOL. A systematic review (Russo, 2011) from the same year suggested that deactivation is discussed in less than half of patients receiving ICD implantation. More recently, Miller et al. (2019), reported that 76% of ICD patients had never had discussions with their HCPs regarding withdrawal of defibrillator therapy (Miller et al., 2019). Moreover, health professionals often do not sufficiently communicate with or involve patients and/or their caregivers or SDM regarding the ICD, and patients often do not recall learning about alternatives to receiving cardiac device therapy (Clark et al., 2011; Carroll, Strachan, de Laat, Schwarz &



Arthur, 2013; Gal & Jaarsma, 2013). This lack of sufficient communication and patient education has serious legal and ethical implications, especially considering that receiving an ICD means patients avoid sudden cardiac death unless the device is deactivated, however patients may not understand or be informed of the nuanced repercussions of these decisions (Strachan, Carroll, de Laat, Schwarz & Arthur, 2011). Even if deactivation is discussed, discussion does not necessarily lead to documentation, which may account for low rates in surveys examining existing AD documentation. Overall these results align with previous studies demonstrating that 30-60% of patients with ICD or MCS report having ADs, but very few directives actually mention cardiac devices or specify their preferences for management at the EOL (Pasalic et al., 2014).

In general, a major limitation of survey-based studies is the assumption that documentation of an AD is evidence of ACP (Connors et al., 1995; Habal et al., 2011; Heffner, 2001; Pasalic et al., 2014; Sadeghi, Walling, Romano, Ahluwalia & Ong, 2016; Schellinger, Longbottom & Briggs, 2011; Tajouri et al., 2012; Tobler et al., 2012b). This conceptualizes ACP as an individualized practice, in which autonomy is exercised at one discrete time point - the moment the AD is signed. This conceptualization fails to recognize ACP as a process that may change over time and deserves continuous attention, re-examination and flexibility. Additionally, there are inherent limitations when examining existence of documentation: documents may exist but may not be filed in the medical record, patients may state they have completed relevant documentation when they have not, and in the majority of studies, relevant SDMs are not surveyed and therefore it is unknown whether or not they are aware of the existence of such documentation (Shapiro, 2015). In Ontario this is especially significant considering the non-legal status of ADs and the role of SDMs.

Unfortunately, the awareness of ACP and prevalence of AD documentation continues to be limited to a minority of HF patients. This is especially concerning considering that there is no marked improvement in AD documentation found in patients receiving cardiac device therapy, despite the complexity that device usage adds to EOL care and recommendations to incorporate ACP into the device implantation process (Ahluwalia & Enguidanos, 2015; MacIver et al., 2016;

Allen et al., 2012). The following section will explore the results of various intervention studies developed to improve this practice within the cardiovascular population.

## 11 ACP Interventions in HF

The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) trial in 1995 was one of the largest studies to examine the impact of ACP interventions on patients' EOL care through both observational data and randomized controlled trial results (Connors et al. 1995). The study trained specialized nurses to elicit and document patient preferences and understanding of disease progress and provide physicians with timely and reliable prognostic information in order to facilitate communication and decision making (Connors et al. 1995). Unfortunately, this four-year study, which followed more than 9000 patients with various chronic diseases (including HF), demonstrated that the nurse-led ACP intervention was largely unsuccessful. The intervention did not improve any outcome measures (median time until DNR written, DNR documentation, pain control, resource use, or presence of undesirable states), despite the fact that the study had sufficient power to detect even small improvements in EOL communication and decision making (Connors et al., 1995)<sup>2</sup>.

Since this study, many clinicians have worked to re-imagine and implement novel ACP interventions designed to initiate or improve ACP practices in various cardiovascular settings. Following the SUPPORT trial, this review identified 11 studies that assessed ACP interventions within the cardiovascular population; settings included preoperative cardiac surgery clinics, cardiovascular rehabilitation programs, homecare organizations, LVAD clinics; community settings and inpatient hospital units (Briggs, Kirchhoff, Hammes, Song & Colvin, 2004; Schellinger et al., 2011; Evangelista et al., 2012; Heffner, 2001; Kirchhoff, Hammes, Kehl,

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<sup>2</sup> As mentioned in the preface, in early years ADs and DNRs were used synonymously, however recently these two concepts have been strongly differentiated, as DNR relates only to resuscitation and ADs are much broader in nature and may refer to aspects of treatment beyond resuscitation.

Briggs & Brown, 2010; Kirchhoff, Hammes, Kehl, Briggs & Brown, 2012; Song, 2005; Sadeghi et al., 2016; Metzger et al., 2016; El-Jawahri et al., 2016; Chan et al., 2018; Takada et al., 2019).

## 11.1 Facilitated Discussion and SDM Interventions

Kirchhoff and Briggs are prominent nurse-researchers in the field of ACP and have contributed to the development of a number of intervention studies that examine the impact of ACP in patients with chronic cardiovascular disease (Briggs et al., 2004; Song, 2005; Kirchhoff et al., 2010; Schellinger et al., 2011; Kirchhoff et al., 2012). In all studies, the patient-centred advance care planning (PC-ACP) or the similar disease-specific advance care planning (DS-ACP) interventions were provided to patients with symptomatic HF (Briggs et al., 2004; Kirchhoff et al., 2010; Schellinger et al., 2011; Kirchhoff et al., 2012) or patients undergoing cardiac surgery (Song, 2005) in conjunction with their surrogate decision makers. This is a one-hour, five-stage interview between a trained facilitator, the patient and the SDM in order to develop an ACP. Five studies provided ACP intervention to patients and surrogates and measured AD documentation rates post-intervention (Schellinger et al., 2011), patient-surrogate congruence and decisional conflict (Briggs et al., 2004; Song, 2005; Kirchhoff et al., 2010), or compared stated preferences with care received at the EOL (Kirchhoff et al., 2012). All studies found improvements in patient-surrogate congruence and decreased decisional conflict in the intervention groups (Briggs et al., 2004; Song, 2005; Kirchhoff et al., 2010), as well as a general willingness to discuss preferences with a trained facilitator (Kirchhoff et al., 2012) and a higher level of ACP documentation compared to non-participants (Schellinger et al., 2011). The major limitation of these studies is the generalizability to other health systems; three of these studies were completed in hospitals already using the *Respecting Choices* PC-ACP intervention program and therefore staff and providers had already adapted to the organizational change required to implement this new practice.

SPIRIT-HF was another structured, guided discussion developed specifically for LVAD patients and their SDMs (Metzger et al., 2016). It was composed of five steps: 1) assessing representations; 2) identifying gaps and concerns; 3) creating conditions for conceptual change; 4) introducing replacement information; 5) setting goals, planning and summarizing (Metzger et al., 2016). During SPIRIT-HF the interventionist (a PhD-prepared nurse) first gained an

understanding of the patients' experiences, thoughts, attitudes, and beliefs, related to their HF and the LVAD, which then facilitated the delivery of targeted, individualized information (Metzger et al., 2016).

More recently, Chan et al., (2018) completed a randomised controlled trial of a nurse-led post-discharge structured ACP program consisting of three home visits; a subset (20%) of their total study sample was comprised of patients living with heart disease. Although the results were not broken down by disease type, overall those who received the ACP intervention exhibited a greater increase in dyadic congruence regarding various EOL care preferences as well as a greater improvement in decisional conflict at the 6-month timepoint (Chan et al., 2018). The experimental group also had significantly higher rates of completion of advance directives and electronic medical record documentation of DNR orders than the control group (Chan et al., 2018). Finally, Takada et al., (2019) developed and pilot tested an ACP support tool for patients living with HF. Both healthcare providers and patients involved in the study concluded that the tool was useful, however the sample size was quite small and would require further testing in order to make broader generalizations regarding utility, effectiveness and influence on patient outcomes (Takada et al., 2019).

Overall, the majority of these studies were conducted in regions with very homogeneous white populations (except for Chan et al., 2018 and Takada et al., 2019); previous research has identified whites as the group most engaged in ACP, which may be related to their ability to identify with individualistic values (Evangelista et al., 2012; Barnato, Anthony, Skinner, Gallagher & Fisher, 2009). Therefore, although these results are not easily replicated in multiracial settings, these findings may suggest that factors related to social location may influence the practice of ACP.

## 11.2 Educational Interventions

Overall there were three studies identified that examined the impact of educational interventions on completion of ACP documentation in cardiovascular populations (Sadeghi et al., 2016; Heffner, 2001; Evangelista et al., 2012). All studies found that patients who received ACP education (through workshop presentation, educational video or palliative care consult session)

demonstrated improved understanding of, and attitudes towards, ACP and that these interventions were feasible in their respective settings (Sadeghi et al., 2016; Heffner, 2001; Evangelista et al., 2012). However, based on documentation rates, educational interventions alone do not increase participation in the ACP process for cardiovascular patients (Heffner, 2001; Evangelista, 2012). This is an especially important finding as research continues to explore this topic. Unlike other health behaviours that may be amenable to improvement via increased education, the ACP process seems to require more than educational interventions to increase participation rates.

In addition to these three studies, El-Jawahri et al. (2016) reported the results of their multi-site randomized controlled trial testing an ACP decision support tool for patients with advanced HF. In this study, patients in the intervention arm received video education on goals of care and various life-prolonging care options, as well as completed an ACP checklist with a trained facilitator (El-Jawahri et al., 2016). The researchers found that patients who received the ACP video intervention were more likely to forego CPR and intubation and had higher mean knowledge scores; this was considered a successful result. This narrow understanding of “successful” ACP as resulting in limited LST demonstrates some of the deep-rooted assumptions that are held regarding the goal of ACP being to limit life-prolonging treatment as opposed to truly examining patient goals, values and preferences, whatever they may be. Unfortunately, this study also reported limitations reflective of the broader ACP literature, in that the sample was predominantly white and therefore results have limited generalizability to more diverse populations.

## 12 End of Life Preferences in Heart Failure

Since the results of the SUPPORT study, clinicians and researchers have also made significant efforts to improve knowledge regarding EOL preferences for patients with HF due to their unpredictable disease trajectory and low rates of ACP participation.

Trade-off tools are used to examine whether HF patients favour quality or longevity of life, and a number of quantitative studies have used these tools to explore how patient preferences might influence treatment decisions (Brunner-La Rocca et al., 2012; Kraai et al., 2013; MacIver et al.,

2008; Stevenson et al., 2008). When exploring the preferences for quality of life compared to quantity of life, findings have been varied and often contradictory. Brunner et al. (2012) used the time trade-off tool (TTO) to demonstrate that both at baseline and at 12 and 18 month follow-up points, the majority (74%) of HF patients were not willing to trade any survival time for excellent health. Conversely, using the same approach, Kraai et al. (2013) found that 61% of their sample of HF patients were willing to trade time in order to achieve improved quality of life, although there was significant variability in the amount of time patients were willing to trade. These studies suggest that patients are heterogeneous in regards to these values, and in general, it cannot be assumed that patient values are fixed, normative or similar to those held by healthcare professionals (Karimi & Clark, 2016). There are also significant limitations to using the TTO, including the hypothetical nature of questions, which make it challenging to correlate research-based responses to the decisions patients would make in reality.

Using a similar yet modified measure called the treatment trade-off tool, MacIver et al. (2008), explored specific treatment preferences relevant to HF patients and rated these preferences based on patient responses. This study also identified that HF patients fall into one of two groups: those who preferred treatments to increase survival time and those who favoured strategies to improve quality of life. The authors noted that there is no way to easily predict which patients will fall into which group, as factors such as gender, ejection fraction, jugular venous pressure, and HF progression did not demonstrate significant effect on treatment preference formation (MacIver et al., 2008). Studies that examine treatment preferences for HF patients have established that preferences are based on factors such as treatment burden, the likelihood of a positive outcome and that overall, preferences for LST change over time (Dev et al., 2012; Fried, Bradley & O'Leary, 2003; Fried, Bradley, Towle & Allore, 2002; Fried et al., 2006, Fried, O'Leary, Van Ness & Fraenkel, 2007; Fried, McGraw, Agostini & Tinetti, 2008; Fried & O'Leary, 2008; Strachan, Ross, Rucker, Dodek & Heyland, 2009; Janssen et al., 2012; Janssen, Spruit, Schols & Wouters, 2011). There is a complex relationship between health status and life-sustaining treatment preferences, which is likely influenced by numerous factors such as symptom burden, the affective state of patients and their family members, environmental and relational stressors and other transient factors (Janssen et al., 2012; Strachan et al., 2009). These studies begin to demonstrate the complexity of the ACP process and the fact that values elicitation is a

challenging and highly individualistic practice and overall, treatment preferences fluctuate and are extremely unpredictable.

Based on the design of these studies, some limitations exist in terms of sample size and type (often using convenience sample) and the use of surveys that limit the number of prescribed outcome choices for patients participating in this research, which hinders an in depth analysis of preference formation (Fried et al., 2003; Fried et al., 2006; MacIver et al., 2016; Janssen et al., 2011; Janssen et al., 2012; MacIver et al., 2008; Strachan et al., 2009). Many studies examined groups of patients with a variety of chronic illnesses and were not HF specific (Fried et al., 2002; Fried et al., 2003; Fried et al., 2006; Fried et al., 2007; Janssen et al., 2011; Janssen et al., 2012). Therefore, these studies often lack nuanced perspectives that may be relevant to HF in particular and do not acknowledge the influence of factors such as device usage and HF specific treatments, which is why the studies by MacIver et al. (2008) and Strachan et al. (2009) are particularly useful. The overarching message from this research is that treatment preferences change over time and with disease progression, they are not easily predictable, and they are influenced by a number of transient factors and thus may not be amenable to elicitation and documentation using the current format of ACP.

## 12.1 Palliative Care in Heart Failure

In recent years, there has been a growing interest in connecting the fields of palliative care and HF care, and examining the impact that palliative care can have for the HF population (Goodlin, 2009; Evangelista et al., 2012; Fitzsimons & Strachan, 2012; Denvir, Murray & Boyd, 2015; McIlvennan & Allen, 2016; McIlvennan et al., 2016; Rogers et al., 2017; Kavalieratos et al., 2017; Lewin & Shaefer, 2017; Lewin et al., 2017; Steinberg, White, Arvanitis, Husain, & Mak, 2017; Janssen, Johnson, & Spruit, 2018; Wiskar, Toma and Bush, 2018; MacIver & Ross, 2018; O'Donnell et al., 2018; McGuinty et al., 2019; Chuzi, Pak, Desai, Schaefer & Warraich, 2019). Importantly, ACP is something that can fall under the broader umbrella of palliative care, however it is also something that can (and often should) occur throughout the HF trajectory and prior to, or outside of, HF patients receiving specialist palliative care. Therefore, this review will

limit this discussion to the role of palliative care specifically in the context of promoting and improving ACP in the HF population.

There has been a specific interest in providing early palliative care and developing tailored palliative care interventions for the HF population. Of note are three key trials: (1) the PAL-HF RCT (Rogers et al., 2017) (2) the ENABLE CHF-PC, which was a pilot feasibility trial (Bakitas et al., 2017; Akyar, Dionne-Odom & Bakitas, 2019), and (3) The Social Worker-Aided Palliative Care Intervention in High-risk Patients with Heart Failure (SWAP-HF) trial (O'Donnell et al., 2018). Both PAL-HF and ENABLE CHF-PC involved providing an interdisciplinary palliative care intervention (primarily a registered nurse or nurse practitioner along with a palliative care physician) to patients living with advanced HF. Both trials incorporated some aspect of ACP into the intervention, although it was not the primary outcome measured, and researchers did not report significant changes in ACP participation rates (Rogers et al., 2017; Bakitas et al., 2017). Despite limited improvements in ACP specifically, both trials demonstrated improvements in quality of life as well as improvements in anxiety and depression in the group of patients who received the PC intervention (Bakitas et al., 2017; Rogers et al., 2017). However, SWAP-HF randomized patients to a social-worker led palliative care intervention that began in the hospital and continued in the outpatient setting; a key outcome in this trial was that more patients in the intervention group had advance care preferences documented in the electronic medical record than in the control group (O'Donnell et al., 2018).

Other than these three trials, the remainder of this literature includes reviews of the HF trajectory, symptom burden, and palliative approaches to HF management (McIlvennan & Allen, 2016; Kavalieratos et al., 2017; Steinberg et al., 2017; Wiskar et al., 2018; McGuinty et al., 2019; Chuzi et al., 2019) as well as needs assessments and suggested models for integrating palliative care into the HF trajectory (Lewin & Shaefer, 2017; MacIver & Ross, 2018; Janssen et al., 2018). Because this area of research is still so new, researchers report that there is limited evidence to support the effectiveness of individual elements of palliative care within the trial interventions (i.e. ACP interventions specifically) (MacIver & Ross, 2018). However, there is evidence to suggest that an integrated HF palliative care program can significantly improve quality of life for HF patients at EOL (Lewin & Shaefer 2017; MacIver & Ross, 2018).



## 13 Patients, Family and Healthcare Provider Experiences with ACP

The following section provides themes generated from the analysis and synthesis of studies that explored the experience of participating in ACP from the perspective of patients, family members and HCP in the cardiovascular context. Studies examining experiences with ACP were largely qualitative in nature, however, the majority of studies fell under the positivist or post-positivist paradigm and were not specifically theoretical or contextual.

### 13.1 Uncertainty

Living with uncertainty is a challenge common to HF patients, family members and HCP and was identified frequently as an influential factor in the ACP process (Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2013; De Vleminck et al., 2014; Dougherty, Pyper, Au, Levy & Sullivan, 2007; Dunlay, Swetz, Mueller & Roger, 2012; Evangelista et al., 2012; Fried et al., 2002; Fluor, Bolse, Stromberg & Thylen, 2014; Greutmann et al., 2013; Jones, Nowels, Sudore, Ahluwalia & Bekelman, 2015). Uncertainty regarding both diagnosis and prognosis is frequently cited as a barrier to initiating or participating in ACP for both patients and providers (Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2013; De Vleminck et al., 2014; Greutmann et al., 2013; Hupcey, Kitko & Alonso, 2016; Im, Mak, Upshur, Steinberg & Kuluski, 2019), as well as uncertainty pertaining to disease trajectory, patient expectations and the knowledge of the kind of treatment patients may want in the future.

Most studies that examined physician or healthcare provider-based experiences cited that uncertainty regarding prognosis and life expectancy significantly hindered their ability to initiate the ACP process with patients. Providers often reported that patients were uncertain or unaware of their diagnosis or prognosis when living with HF, which encouraged avoidance or deflection when patients asked questions that could lead into ACP discussions (Ahluwalia, Levin, Lorenz, & Gordon, 2012; Ahluwalia, Levin, Lorenz & Gordon, 2013). This sentiment was also supported by the report that feeling relatively certain of a patient's prognosis or having access to better data regarding life expectancy facilitated the ACP process (Greutmann et al., 2013; Ahluwalia et al., 2012). Interestingly, HF patients did not find specific estimates of life

expectancy useful in their decision making and future planning (Dougherty et al., 2007; Greutmann et al., 2013). This demonstrates an incongruity between the assumptions providers make regarding what information patients require and what type of information patients may actually value.

In studies exploring the patient perspective, patients reported that their lives were dominated by uncertainty; they were unsure of their life expectancy, what hopes they could have for recovery or for the future, and they were uncertain as to how to discuss EOL issues with providers and family members (Jones et al., 2015; Dougherty et al., 2007). Zwakman et al. (2018) characterized this phenomenon as patient “ambivalence” (p. 1311). This uncertainty translated to the SDM experience as well; literature demonstrated that SDMs are often unprepared, overwhelmed and unsuccessful at predicting the patient’s wishes due to the high level of uncertainty in clinical situations that can arise in the HF trajectory (Hall, 2008; Evangelista et al., 2012; Fried et al., 2002). Spouses also demonstrated a significant amount stress and uncertainty surrounding surrogate decision making as well as ICD management and deactivation (Hall, 2008; Shapiro, 2015; Fluor et al., 2014; Jones et al., 2015). They were uncertain of how to appropriately adjust to living life with a spouse suffering from HF and held uncertain expectations for the future for themselves and their family members (Fluor et al., 2014; Jones et al., 2015). Although prognostication is inherently difficult in HF, this synthesis suggests that patients and family members may not value or require specific estimates of life expectancy, but rather would appreciate an acknowledgement of the uncertainty they are experiencing and an openness to discussing future care options.

## 13.2 Discomfort Discussing EOL Care

The results of this review demonstrate that patients and family members are often open to participating in ACP conversations but have different levels of readiness for participating in prognostic discussions (Habal et al., 2011; Greutmann et al., 2013; Fried et al., 2008; Gordon, O’Riordan, Dracup, De Marco & Pantilat, 2017; Zwakman et al., 2018), while providers experience discomfort with discussing EOL care or death which hinders their ability to initiate the ACP process (Habal et al., 2011; Greutmann et al., 2013; De Vleminck et al., 2014; Ahluwalia et al., 2012; Ahluwalia et al., 2013; Gigon, Merlani & Ricou, 2015). Healthcare

practitioners reported various levels of discomfort with the ACP communication process; cardiologists in particular self-rated their EOL communication skills as lower than other specialties and patients reported lower ratings for the EOL communication skills of their cardiologists compared to their general communication skills (De Vleminck et al., 2014; Ahluwalia et al., 2012; Ahluwalia et al., 2013; Gigon et al., 2015; Janssen et al., 2011). Discomfort was most frequently caused by lack of adequate training or skill, lack of communication strategies, lack of confidence, unfamiliarity with the components of ACP, or an overall aversion to discussing EOL issues and death (De Vleminck et al., 2014; Ahluwalia et al., 2012; Ahluwalia et al., 2013; Gigon et al., 2015). Multiple studies found that providers were often unfamiliar with the legal aspects of ACP (especially in relation to ICD deactivation) and missed opportunities to respond to patient questions or concerns regarding EOL care (De Vleminck et al., 2014; Greutmann et al., 2013; Ahluwalia et al., 2012). This also aligns with factors such as increased education, training and provision of communication strategies being frequently cited as factors that would improve provider comfort and increase uptake of ACP conversations (De Vleminck et al., 2014; Greutmann et al., 2013; Ahluwalia et al., 2012; Gigon et al., 2015).

Interestingly, in settings where a trained, non-physician facilitator led ACP conversations, discomfort and uncertainty were not identified as concerns because the facilitator was not responsible for prognostication and was experienced with the emotional requirements of ACP conversations (Song, 2005; Briggs et al., 2004; Evangelista et al., 2012; Schellinger et al., 2011; Kirchhoff et al., 2010). This suggests that designating a specific service or introducing a specific role for trained facilitators (non-physician healthcare professionals comfortable and experienced in ACP) may be very beneficial to establishing successful ACP practices.

### 13.3 Time and Timing

A number of studies identified healthcare providers' lack of time as a barrier to addressing ACP, as it is often only one of multiple competing priorities during brief clinic appointments (Ahluwalia et al., 2012; Ahluwalia et al., 2013; Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2014). This issue is also linked to the problem of timing. Many providers reported being unable to find the appropriate 'time' or an inability to identify key 'moments' to introduce the

idea of ACP in a fashion that was comfortable for patients, family members and themselves. There was also a belief that others are responsible for initiating ACP conversations, whether that was healthcare providers from other specialties, patients or family members (Chandar et al., 2016; Gigon et al., 2015; Zwakman et al., 2018). A lack of patient-initiation was cited as a barrier to successful ACP discussions between patients and providers (De Vleminck et al., 2014; Gigon et al., 2015); this also aligns with the idea of readiness and the fact that many providers assumed patients and SDMs were not ready to embark on ACP conversations when in reality the majority of patients are willing to discuss ACP, and occasionally suggested it may have been more beneficial earlier in the disease trajectory (Greutmann et al., 2013; De Vleminck et al., 2014; Habal et al., 2011; Metzger, Song & Devane-Johnson, 2016).

## 13.4 Relationships

The relational aspect of patient autonomy is extremely relevant when examining the practice of ACP which heavily relies on strong collaboration between patients, SDMs and HCP. Therefore, it is not surprising that including family members in the ACP process was revealed as a facilitator to the practice (Schellinger et al., 2011; Shapiro, 2015; Hall, 2008; Fluor et al., 2014). Considering that a large component of ACP focuses on appointing an SDM, it is especially important to ensure that SDMs are aware of the requirements of surrogate decision making and are sufficiently included in the exploration of the patient's values, goals and wishes (Shapiro, 2015). The patient-provider relationship also plays an important role with a strong, longstanding and trusting relationship with the patient being cited as a facilitator of ACP (Greutmann et al., 2013). Shapiro (2015) argues that a well-prepared SDM is much more useful than a document of potentially irrelevant healthcare wishes. Therefore, significantly more effort should be placed on examining the experience, responsibilities and perspectives of surrogate decision makers.

## 13.5 Maintaining Hope

A commonly cited reason for failing to participate or initiate ACP was not wanting to remove hope, either from patients or from family members, and preferring to focus on staying alive rather than think about death (De Vleminck et al., 2014; Ahluwalia et al., 2012; Greutmann et al., 2013). There is a distinction between discussing death and discussing the care that one receives prior to death or during incapacity. It may be useful to frame ACP not as an EOL conversation,

but as a conversation that prepares surrogates for the complex decision making that is unavoidable during potential health crises and hospitalizations that accompany the HF illness trajectory. Approaching the conversation in this manner may be more accessible for providers and less threatening to patients.

## 14 Discussion

This review has highlighted a number of themes relevant to the experience of ACP for patients, family members and HCP in the context of chronic cardiovascular disease. Based on this analysis, there are some general conclusions that can be drawn. Firstly, there are no studies to date that have employed a critical approach to understanding ACP from the perspectives of various individuals involved. The majority of qualitative studies have focused on the perspectives and challenges from the viewpoint of the HCP who is frequently a physician and has the ability to ‘control’ the delivery of ACP (Johnson et al., 2016). The qualitative research in this field has utilized a highly positivist stance (i.e., did not explore relationships or power dynamics) and has followed the individualistic paradigm that is central to quantitative biomedical research (Killackey, Peter, MacIver & Mohammed, 2019b). Few studies have examined the experience of HF patients and their families who participate in ACP and whether they view this process as a means to secure their autonomy, or whether they value the individualistic form of autonomy that this practice currently promotes (Johnson et al., 2016; Singer et al., 1998). The use of critical case study for this research will therefore offer a methodological contribution to the literature, and will provide an alternative framework with which we may be able to better understand the holistic experience of ACP.

Secondly, intervention studies have failed to become fully integrated into the management of the HF population despite research efforts and guideline recommendations. Although occasionally successful when provided within very specific contexts (i.e. homogenous, North American, white populations), it is clear that ACP interventions have not succeeded in sustaining significant uptake in the cardiovascular population based on the low rates of awareness and prevalence of this practice for both patients and providers (Habal et al., 2011; Ahluwalia et al., 2013; Greutmann et al., 2013; Tobler et al., 2012b). Many studies are designed under the premise that patients value a document-driven process of ACP modeled after the practice of informed

consent, demonstrated by the focus on documentation and individualized interventions (Connors et al. 1995; Habal et al., 2011; Heffner, 2001; Pasalic et al., 2014; Sadeghi et al., 2016; Schellinger et al., 2011; Tajouri et al., 2012; Tobler et al., 2012b). In addition, the majority of outcome measures used to demonstrate the impact of ACP interventions (such as prevalence of written ADs or identification of SDMs) are not only inadequate but are incongruent with the way this practice is defined: as a continuous process that is focused on articulation of values and beliefs.

Finally, the research demonstrates that treatment preferences change throughout the course of a chronic disease and cannot be predicted (Fried et al., 2002; Fried, Bradley, & O’Leary, 2003, Fried et al., 2006, Fried et al., 2008; Janssen et al., 2011; Janssen, Spruit, Schols & Wouters, 2013). Yet numerous studies have focused on aggregating treatment preference data in order to draw conclusions that may be irrelevant for individual patients who experience their illnesses within the context of the relationships and social forces that have shaped their identity (Fried et al., 2002; Fried, Bradley, & O’Leary, 2003, Fried et al., 2006, Fried et al., 2007; Janssen et al., 2011; Janssen et al., 2013; Johnson et al., 2016). The ACP process is complex, and the majority of qualitative studies have focused on the perspectives and challenges from the viewpoint of HCP (Johnson et al., 2016). As mentioned, the qualitative research in this field is highly positivist and follows the individualistic paradigm that is central to quantitative biomedical research. Few studies have examined the experience of HF patients and their families who participate in ACP and whether they view this process as a means to secure their autonomy, or whether they even value the individualistic form of autonomy that this practice currently promotes (Singer et al., 1998; Johnson et al., 2016).

Overall, this synthesis of studies identifies two assumptions that have been made on the part of health researchers studying ACP within the cardiovascular population. These assumptions are:

1. Cardiovascular patients value individualistic accounts of autonomy within the context of their chronic illness and EOL care.
2. Cardiovascular patients understand ACP and view this practice as a means to support their autonomy within the context of their chronic illness and EOL care.

Based on this analysis, there are many aspects of this practice that require further exploration and explanation however the focus of this review is to examine how patients and families perceive

the practice of ACP and how this experience fits within their social world. Two main ideas will be discussed: firstly, the idea of ACP as a practice that is mitigated through relationships both with others and with the self, and secondly, the idea that ACP is an institutionalized practice mitigated by the values and priorities of Western societies.

## 14.1 ACP as a Relational Practice

### 14.1.1 Relationship with Others

ACP is an inherently relational process as it relies heavily on the involvement of at least one SDM (and frequently involves many relationships with family and friends), as well as the involvement of key healthcare providers (Hall, Sanford & Demi, 2008). Patients experience EOL decision making as a social process (Hopp, Thornton & Martin, 2010); several studies suggest they are most concerned about relieving the burden placed on loved ones and are happy to provide surrogates with leeway when making challenging health decisions on their behalf (Sudore & Fried, 2010; Johnson et al., 2016; Singer et al., 1998). The perception of decision making as a social process demonstrates the need to provide ACP in a way that is targeted not only to individual patients but that also recognizes the role and responsibility of SDMs and accounts for the influence of the social, political and environmental forces that surround the patient and family.

When exploring the relationship between healthcare providers and patients in the context of ACP, there are assumptions being made on both sides of the relationship. This review demonstrates that providers assume patients require specific prognostic information in order to participate in ACP, and when they are unable to provide this information they do not initiate the ACP process (De Vleminck et al., 2014; Greutmann et al., 2013), although patients do not always value or require specific life expectancy estimates for their decision making (Dougherty et al., 2007). Conversely, recent research in the surgical setting has demonstrated that patients frequently assume that their healthcare providers share their values, know when they are entering the EOL phase, and will make challenging EOL decisions for them (MacIver et al., 2016; Nabozny et al., 2017). Under the current practice, it is the patient themselves or the SDM who will be expected to make these decisions. The lack of common assumptions between providers and patients is problematic and underscores the need for improved communication within the

context of patient-provider relationships in advanced chronic disease as well as highlights the importance of personal and social relationships on the experience of ACP.

### 14.1.2 Relationship with Self

A key finding of this review, individual treatment preferences do not necessarily represent stable core values, and therefore cannot be accessed or extracted from patients and documented at any given point, contributes to the current challenges implementing ACP processes in clinical practice (Janssen et al., 2011; Janssen et al., 2012). The current documentation-focused process also assumes that patients have sufficient self-awareness to allow the clear articulation of very complex values, and sufficient confidence to express these values to family member and healthcare providers, even if these perspectives are in conflict with biomedical and societal norms. Karimi & Clark (2016) have identified that self-related values are linked to patients' perceptions and sense of self and can be highly motivational when examining concepts such as patient self-direction. Therefore, autonomy-enhancing competencies that are mediated within the self but stem from a relational context likely contribute the ability of individuals to be self-directed and participate in ACP (Karimi & Clark, 2016; McLeod & Sherwin, 2000). This review also demonstrates the overwhelming force of uncertainty that is experienced by patients, family members and healthcare providers. The role of uncertainty is significant when exploring patients' capacity for autonomy and ability to make decisions within the context of life-limiting illness. Overall, these concepts warrant further study, as the capacity for individuals to enact autonomy by drawing on relational competencies has not yet been examined within the context of chronic disease.

## 14.2 ACP as an Institutionalized (and Undervalued) Practice

### 14.2.1 Time

Limited time and increasing scarcity of resources continue to be significant problems in healthcare systems in high income countries as the aging population grows and the medical complexity of patients continues to increase. However, lack of time would not be an acceptable reason for failing to perform adequate physical assessments, device checks, or diagnostic tests. Therefore, in this review, the finding that providers lack time to initiate ACP conversations (De



Vleminck et al., 2013; De Vleminck et al., 2014; Gigon et al., 2015; Greutmann et al., 2013) could be understood as a demonstration or reflection of societal priorities. In a society that highly values the biomedical model and scientific interventions over interpersonal and psychosocial support, ACP is seen as an uncomfortable, challenging and time consuming intervention. Therefore, it is unlikely that merely increasing length of appointment time would sufficiently encourage providers to begin these important conversations without modifications in training, care routines, and an overall shift in the dominant paradigm of the biomedical model.

## 14.2.2 Responsibility

This synthesis demonstrated that there is no one service, provider or profession who is solely responsible for the provision of ACP. Because of this and the lack of clarity regarding the point at which ACP should be initiated, we see physicians shifting responsibilities to colleagues in other specialties, as well as providers shifting responsibility to patients to initiate these conversations. Acts such as the Patient Self Determination Act (1990) and the Health Care Consent Act (1996) have transferred responsibility for medical decision making, and responsibility for the consequences of medical decision making, from healthcare providers to patients and their family members. Neoliberalism, with its emphasis on individualism, self-care and self-sufficiency, utilizes the language of autonomy, empowerment and control as a way to download responsibility for decision making onto patients and families, which further complicates the process of ACP (Petersen, 1997; Coburn, 2000).

Overall, this portion of the review has provided insight into the individualistic underpinnings of the current practice of ACP and explored the challenges of successfully integrating ACP into the care of patients living with HF. Current conceptualizations of ACP fail to recognize the influence of personal relationships and social forces on the ability of individuals to make healthcare decisions and, in general, may be incongruent with the way chronic illness and EOL decision making is experienced.

# 15 Relational Autonomy in Advance Care Planning

Currently there are no empirical studies that have employed the concept of relational autonomy as an analytical framework in the examination of ACP in the HF population. Although relational autonomy has been explored theoretically in relation to EOL care and family decision making (Chan, 2004; Broom & Kirby, 2012; Drought & Koenig, 2002, Ho, 2008) there are a select few publications (both theoretical and empirical) that highlight the role that relational autonomy may play in understanding the experience of ACP specifically (Robins-Browne, Hegarty, Guillmen, Komesaroff & Palmer, 2017; Lin, Cheng & Chen, 2018). The following section will provide a brief overview of the literature relevant to this topic area.

Beginning in the late 1990s, Singer and his colleagues demonstrated that the perspectives of patients participating in ACP do not fully support the traditional academic assumptions used to justify this practice. In a qualitative study interviewing patients living with end-stage renal disease (Singer et al., 1998), Singer noted significant incongruity between the way ACP was justified theoretically (using the philosophical underpinnings of respect for individual autonomy) with the way ACP was experienced by patients and family members. From their perspective, ACP was understood to be a social process occurring within the context of relationships with close loved ones, and was focused on relieving the burden placed on others (Singer et al 1998). Building on this, Singer argued that liberal autonomy does not account for the value of personal relationships that arise in ACP (Ikonomidis & Singer, 1999). Overall, Singer did not explicitly suggest the use of relational conceptions of autonomy, but suggested that the focus of ACP be broadened to include the role of loved ones in the process, and recommended that ACP interventions target the family as well as the patient (Singer et al., 1998)

Following this, Ho argued for the re-examination of the concept of individual autonomy by examining the characteristics of families and their role in medical decision making (Ho, 2008). Although this theoretical essay did not focus specifically on the process of ACP, Ho explicitly used relational autonomy to provide an examination the family's role in medical decision making. She suggested that given the realities of stress and vulnerability experienced in illness, some patients may want others who know them well to help them make appropriate decisions that fit their relational identity (Ho, 2008). Ho (2008) argues that given our relational identity and intertwined interests and responsibilities, respect for patients' agency cannot be solely based

on providing the opportunity to “independently choose off a therapeutic menu” (p. 132). This sentiment is echoed in the recent trend in ACP research to move away from making specific treatment decisions in advance using a checklist format. In conclusion, they suggest that there is a role for healthcare providers to contextualize medical options for patients within their social worlds and relationships (Ho, 2008).

In more recent empirical work, Robinson (2011) published a descriptive qualitative study exploring the effectiveness of an ACP intervention with patients who were newly diagnosed with lung cancer and their SDM. Although this study did not explicitly employ a relational autonomy lens from the outset, Robinson noted that the idea of ACP being theoretically rooted in a traditional, or individualized notion of patient autonomy was not aligned with the relational process that unfolded in their study. Through data collection they noted, like Singer et al. (1998), that ACP was not necessarily about preparing an SDM but was a deeply relational process where meaning, values and preferences were negotiated in conversation with others (Singer et al., 1998; Robinson, 2011). Robinson concluded by suggesting that an approach to ACP that embraces relational autonomy would be more congruent with the experiences of patients and would provide a stronger foundation for meeting the needs of families. Their overall suggestion was to conduct research to determine the most effective way to implement a relational approach to autonomy in ACP.

More recently, Johnson et al. (2016) completed a systematic review of perspectives of ACP in the oncology population, and Saddiqui (2016) completed a theoretical overview of the challenges currently facing ACP. Saddiqui (2016) discussed the benefits of using a relational autonomy approach as an alternative to individual autonomy. In line with Singer et al., (1998) and Robinson’s (2011) findings, they noted that patients may not prioritize individual autonomy and may place more value on the impact of ACP on their family members. Johnson et al. (2016) reported similar findings of their systematic review, stating that the notion that ACP is primarily concerned with the right to self-determination through control over treatment choices may misrepresent the way ACP actually occurs as a relational, emotional and social process. Importantly, they highlighted the fact that the choices people make and their capacity to implement choices is dependent on existing relationships and the context within which they are

operating (Johnson et al., 2016). Although, like Singer et al., (1998), they did not explicitly reference relational autonomy, Johnson et al. (2016) identified that agents are both dependent and constrained by their existing relationships and the social contexts which frame their decision making. This is further evidence that the experience of ACP may be better understood using the framework of relational autonomy and the concept of social location.

Moreover, Robins-Browne et al. (2017) recently examined the role of “relational knowing” in the process of ACP for older patients in the community and their SDM. Although the authors did not provide a clear definition of “relational knowing,” they discussed the role of autonomy and how relational knowing may provide a different way of understanding and approaching the ACP process. Overall, the results of their qualitative study concluded that the dominant model of decision making, which underpins ACP, may be partial and incomplete, and although individualized concerns are of importance, but they are not all that matters to people who are faced with the significant challenges associated making decisions about medical treatments (p. 132). Finally and most recently, Lin et al. (Lin, Cheng & Chen, 2018) and Gomez-Virseda et al. (Gomez-Virseda, de Maeseneer & Gastmans, 2019) both provided strong arguments for employing relational autonomy as a key concept to guide EOL care and decision-making by examining how relational autonomy connects to traditional values in Asia (Lin et al., 2018) and by synthesizing the current literature using relational autonomy in EOL research (Gomez-Virseda et al., 2019).

In conclusion, although none of these studies were specific to the cardiovascular population, this comprehensive overview has outlined the strong evidence for using a relational approach to autonomy to better understand the experience in ACP. This also highlights the significance of this study, as it will be the first to explicitly use relational autonomy theory as an analytical framework in an empirical examination of ACP in the HF population.

## 16 Conclusion of Literature Review & Recommendations

Although ACP has existed for more than 30 years and support for the process has been established from both healthcare providers and patients, it continues to be a challenge to implement and sustain. This review adds to the field by describing the current state of

interventional and exploratory research regarding ACP in the cardiovascular population as well as provides an account of experiences and challenges specific to the ACP process as a component of chronic illness management. Most significantly, this review highlights the social and relational nature of ACP and EOL decision making for patients living with cardiovascular disease and exposes the current incongruity between the individualistic underpinnings of ACP as it is provided in clinical practice compared to the relational reality experienced by patients, family members and healthcare providers.

Recommendations for future work include further inquiry into the experience and decision making process of patients and SDMs who are capable of participating in ACP during the HF trajectory (MacIver et al., 2008). More research regarding the perspectives of patients and SDMs on the contextual factors that influence the uptake of ACP (such as social location), the effect of ACP on interpersonal relationships and the experience of ACP for SDMs and others involved in the process would also be beneficial (Andreassen, Neergaard, Brogaard, Skorstengaard, & Jensen, 2015; Shapiro, 2015). Recent research suggests that healthcare providers have a responsibility to help patients select an appropriate SDM who is adequately prepared to be a strong and effective advocate; therefore, research needs to expand to include an exploration of the experiences of surrogates in order to move away from an overly individualistic understanding of ACP (Shapiro, 2015). Finally, an exploration of the societal influences that shape the chronic illness and dying experience in high income countries may be fruitful; this could reveal higher-level factors that restrict individuals from following through with ACP despite its widely acknowledged importance.

Table 1: Literature Review Search Results

Database	Total Retrieved	Total Unique	Duplicates
CINAHL	854	819	35
MEDLINE	163	134	29
MEDLINE In-Process	18	18	0
PsycINFO	17	11	6
Scopus	175	130	45
Sociological Abstracts	22	22	0
Total	1249	1134	115

Hand-search articles: 10

Figure 1: Search Strategy Flow Chart

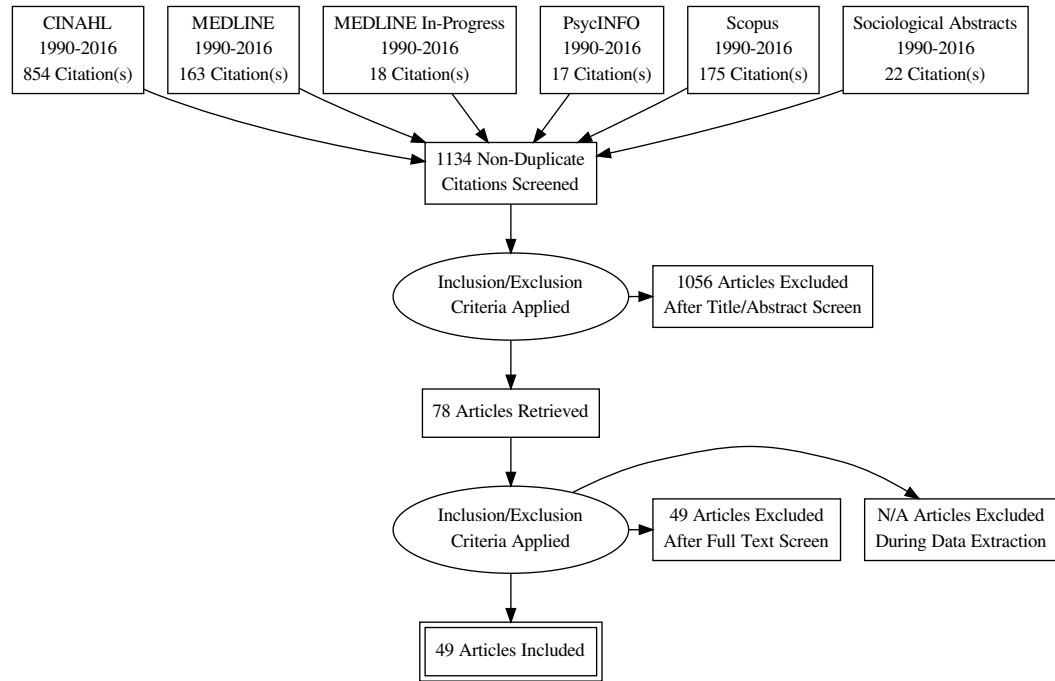


Figure 1: Search Strategy Flow Chart

- See Appendix C for Eligibility and Exclusion Criteria

## Chapter 4

### Methodological Approach

In this chapter I describe the methodological approach that guided this research. First, I examine case study as a research methodology, with specific focus on qualitative case study research in the health sciences. Next, I describe the fit between case study and my epistemological and ontological positioning and provide justification for using case study methodology in this study. Then, I examine the sampling strategy and data collection techniques for this study, as well as data analysis plan. Finally, I conclude this chapter with a discussion of methodological rigour and the ethical considerations of conducting this study with the population of interest.

### 17 Case Study Methodology

There has been a long tradition of case study methodology in the social sciences, as well as in healthcare, economics and politics in order to explore, describe or explain a phenomena or social process and provide holistic and contextualized understandings (Luck, Jackson, Usher, 2005; Yin, 2009). Case study can be defined as an empirical inquiry that investigates a contemporary phenomenon in depth within real-life settings (Yin, 2009). The goal of case study research is to intensively study a relatively bounded phenomenon, with a strong focus on social context (Yin, 2009; Stake, 2000). Many authors have suggested a variety of ways in which to bind cases in order to ensure feasibility and avoid trying to answer a question that is too broad (Baxter & Jack, 2008). Binding cases by time, place, activity, definition or context have all been proposed as methods to delimit and define the case under examination and is part of the methodological process (Creswell, 2003; Stake, 2000; Miles & Huberman, 1994). Delimiting these boundaries allows the researcher to highlight what will (and will not) be studied, and indicates the breadth and depth of a qualitative study in addition to defining the sample (Baxter & Jack, 2008). This process has also been described as determining the “unit of analysis” (Yin 2009, p. 30) or defining the “case-purpose dyad” that is mediated by the theoretical framework (Carolan, Forbat & Smith, 2015, p. 8). The definition of the case will be fully discussed later in this chapter.



A key strength of case study research is the flexibility of the research approach, which allows for intensive focus on the phenomena of inquiry; this differentiates case study from other well-established qualitative methodologies, which often dictate specific design decisions (Meyer, 2001; Sandelowski, 2011; Yin, 2009; Stake, 2000; Flyvbjerg, 2011). Case study is characterized by the use of multiple data collection techniques and data sources, which allows researchers to gain a holistic and in-depth understanding of the case (Carolan et al., 2015). Overall, case study is defined by the choice of case as opposed to the choice of methods (Luck, Jackson, Usher, 2005) and this methodology allows the research to tailor the research approach to best explore the study phenomenon (Yin, 2009; Flyvbjerg, 2011; Meyer, 2001).

For the purposes of this research project, I used a qualitative multiple-case study approach guided by the concept of relational autonomy. Multiple-case studies, also called collective case studies (Yin, 2009), are used to explore differences within and between cases (Baxter & Jack, 2008). Using relational autonomy theory to guide the selection of multiple cases allows for the exploration of a variety of experiences; such findings can be used in both comparison and contrast to gain new analytical insights to the ACP experience (Baxter & Jack, 2008). These cases will also qualify as instrumental cases (Stake, 2000), as they will be used to contribute to the refinement and development of feminist ethical theory and relational conceptions of autonomy (Baxter & Jack, 2008). Instrumental cases can be defined as cases that are examined in order to provide insight into a topic, which in this case would be the process of ACP in HF, as opposed to an intrinsic case study that is explored merely for interest in the case itself (Stake, 2000).

My approach was informed by aspects of Yin's (2009) and Stake's (2000) conceptualization of case study methodology. Although Yin (2009) has been noted to hold a post-positivist perspective and their suggestions regarding rigour align with this perspective, their work has been helpful in defining case study as a methodology and providing guidelines regarding design and sampling. In contrast, Stake (2000) holds an interpretivist perspective and provides insight into aspects such as contextualization of cases, case selection, triangulation and the ability of case study to contribute to and refine theory. Additional authors such as Sandelowski (2011),

Dooley (2002), Flyvbjerg (2011), Cresswell (2003, 2007) and others have contributed to the development of this approach.

One of the main criticisms of case study methodology is that its flexible design leads to a lack of rigour compared to alternative methodologies that provide more specific guidelines for data collection and analysis (Meyer, 2001; Flyvbjerg, 2011). Rigour in case studies can be achieved by approaching the research in a principled way that ensures ontological, epistemological and methodological congruency throughout the research process, using multiple data sources to enhance credibility, and taking active measures to establish researcher reflexivity (Meyer, 2001; Carolan et al., 2015; Baxter & Jack, 2008). Case study also allows for triangulation of multiple data points in order to highlight multiple perspectives on a phenomenon (Stake, 2000), and the flexible and responsive nature of the researcher's relationship with participants allows for enhanced examination of theoretical concepts in an empirical setting (Meyer, 2001; Sandelowski, 2011). Establishing this type of "empirical intimacy" (Sandelowski, 2011, p. 153) was important, as this study was the first to empirically examine relational autonomy in relation to ACP in the HF population.

## 18 Justification for Methodological Choice

Case study methodology served the purposes of my research for two main reasons. Firstly, understanding the social context is necessary for developing a comprehensive understanding of a particular phenomenon (Yin, 2009) and the goal of this study was to provide a broader examination of social forces that shape the experience of ACP for HF patients. In general, case study research seeks to answer 'why' and 'how' questions and excels by adding strength to what is already known in an area of research (Dooley, 2002). For this dissertation, research questions will explore *how* people living with HF understand ACP, *how* they express autonomy when participating in ACP, and *how* social location may mediate this experience. ACP research has been taking place for over 30 years without producing significant improvement in participation rates. Therefore, by using a critical perspective to highlight taken for granted assumptions (Kincheloe & McLaren, 2000) and employing case study approach, this work provides an in-depth understanding of the relational and social context of ACP in order to build on the existing literature.

Secondly, relational autonomy, social location and medicalization are key theoretical concepts within my study. Relational autonomy is the recognition that autonomy is both defined and pursued in a social context and that social location significantly influences the opportunities an agent has to develop or express autonomy skills (McLeod & Sherwin, 2000). Social location consists of ascribed social identities (i.e. gender, race, sexual orientation), and social roles and relationships (i.e. occupation, familial positioning, etc.) (Grasswick, 2013). Oppression is the result of intersecting power relationships that interfere with an agent's ability to develop or exercise autonomy effectively, is a therefore a component of social location (McLeod & Sherwin, 2000; Sherwin, 1992). Medicalization is the unintentional or intentional expansion of the domain of medical jurisdiction, where successful medicalization involves individuals, groups and cultural institutions viewing (or coming to view) a domain, problem, condition, choice or life circumstance in medical terms (Morgan, 1998). The tenets of case study methodology strongly support employing a previously developed and established philosophical framework, such as feminist ethical theory and relational autonomy, to guide the research process (Yin, 2009). To align with my feminist case study approach, each case will be linked to relevant political, social, historical, and personal contexts (Dooley, 2002) in order to examine the influence of intersecting social forces on the ability of people to exercise autonomy. By relying on multiple sources of evidence as well as a strong theoretical framework (Dooley, 2002), this study contributes to relational conceptualizations of autonomy by facilitating a deeper understanding of how autonomy is experienced within the ACP process.

## 18.1 Defining the Case

A key aspect of case study research is delimiting and defining the case. Therefore, significant attention has been paid to outlining the boundaries of the case while also allowing for flexibility as the research progresses (Sandelowski, 2011, p. 155; Ragin, 1992). In this study, a single case consisted of the patient with advanced HF, defined by using New York Heart Association classifications level III-IV, AHA stage D (See Appendix A). Starting from this person, each case expanded to include others who contributed to or influenced the ACP experiences of each patient. This allowed cases to include people such as: family members, close friends, personal lawyers, as well as healthcare providers that care for the patient both within and outside of the recruitment site. Using case study also allowed for relevant documents, such as pre-existing

living wills, advance care directives, POAPC designations, and information that patients have received regarding ACP to be included in the make-up of the case (i.e. Speak Up workbooks, institutional information brochures, etc.). Documents were also sampled from the wider institutional spheres, to incorporate data such as clinical practice guidelines or policy documents, clinical or administrative documentation forms, e-learning modules for clinicians, pamphlets and online patient education documents to provide broader context. An overview of the data that was collected and compiled to construct each case is provided at the beginning of Chapter 5.

As noted in the literature review, physicians can be highly influential in the initiation and control of ACP. However, recent research has demonstrated that nurses play a particular role in the ACP process, specifically acting as coaches for patients as they move through the HF disease trajectory (You et al., 2017). Therefore, when possible, data collection sought to highlight the relationship patients have with their HF nurses and how this may influence their experience of ACP. Providers such as social workers, ethicists, and physicians were also interviewed to support the construction of a particular case if participants identified them as people that have been supportive or have contributed to the ACP process.

## 18.2 Definitions of Advance Care Planning

As previously discussed in the literature review, for the purposes of this study I defined ACP as a process that enables people to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers (Rietjens et al., 2017; Sudore et al., 2017). This definition is not limited to discussions regarding EOL care specifically because I was interested in the experience of autonomy throughout the advanced HF trajectory and at various time points in the decision making process. As an example, patients “participating in ACP” may be deciding on a substitute decision maker, exploring treatment options such as CRT/PM/ICD or therapies such as TAVI or MitraClip®, moving either in or out of the in-patient care setting, etc. Because ACP involves the identification of values, goals and preferences, this study also examined how patients make important decisions about their lives in general, in addition to treatment-related decisions. Examples include making decisions about work, relationships, finances, family, life goals, etc. The definition of participating in ACP was

left broad in order to gain insight into the various facets of advanced HF treatment and the experience of decision making at various stages of illness or exacerbation.

## 19 Sampling and Recruitment

### 19.1 Location of the Study Site

This study was conducted at two study sites in order to facilitate maximum variation in sample characteristics. Both sites were outpatient HF clinics at large urban academic hospitals. Despite these similarities, these clinics have distinct client populations. The first site, a more specialized centre, has a relatively young client base (average age 55 years old), and sees complex HF patients with fewer co-morbidities who are seeking advanced therapies such as transplantation or LVAD implantation. The second site serves an older demographic of patients who have less complex HF but are often living with additional co-morbidities, usually related to frailty or advanced age, and who are not candidates for advanced therapies. Both clinics employ a multi-disciplinary approach to care. These sites provided a rich research environment as clinicians at these clinics often have longstanding relationships with their patients and have many opportunities to discuss or introduce the ACP process. The use of two study sites was beneficial as it allowed for a wider pool of potential study participants and also allowed for comparison of experiences between the two study sites, which enhanced the analytic depth of the study.

### 19.2 Sampling Strategies

Purposeful sampling was employed in order to identify patients with a variety of experiences (Ritchie, Lewis & Elam, 2003; MacIver et al., 2016) and facilitated an in-depth exploration of HF patients in conjunction with their relevant relationships and social responsibilities. Purposeful sampling allows for cases to be chosen because they possess particular features or characteristics; these can relate to socio-demographic characteristics or specific experiences, behaviours, or social roles (Ritchie et al., 2003).

As the experience of ACP within the framework of relational autonomy was the focus of the analysis, I purposefully sampled patients that have advanced HF and therefore have experience participating in healthcare decision making within their illness trajectory (Ritchie et al., 2003).

In order to highlight a diversity of rich cases, I aimed for maximum variation within the purposefully selected participants (Patton, 2002). Employing maximum variation sampling encouraged a range of cases with diverse social locations; therefore I sought to recruit a sample with demographics that varied in age, gender, race and/or ethnicity, socioeconomic status, and employment status (Ritchie et al., 2003). Because ACP relies so heavily on social support, specifically in the form of a substitute decision maker, my cases also varied regarding family structure, social network and relationship status. I aimed to select participants with varying levels of disease status, modes of treatment and device usage (see Appendix D: Inclusion Criteria). Recruitment was flexible depending on when eligible patients became available, but targeted approximately one case per month to be recruited, as each case may include several people in addition to document analysis. While recruiting, a participant may have been rejected in favour of another if the case did not further the analysis or was similar to previous cases.

### 19.3 Recruitment Strategies

1. Attending physician or nurse practitioner identified patients they believed would be a candidate for the study (See Appendix D: Inclusion Criteria)
2. Member of HF team approached patient to briefly explain the study and ask if they were interested in meeting the researcher (See Appendix E: Study Introduction Script)
3. Researcher provided information package, obtained informed consent or followed up at a later time

### 19.4 Measures for Screening Participants

The attending physician or nurse practitioner informally screened participants prior to referring them to the study. Healthcare providers were instructed on the inclusion and exclusion criteria prior to beginning recruitment, as well as the requirement that participants be sufficiently capable to voluntarily consent to study participation. Due to the longstanding nature of the relationships between HF healthcare providers and their patients, HF clinicians were in the ideal position to refer appropriate patients to the study and their clinical judgment was used as opposed to a formal screening requirement, which could unnecessarily exclude some patients.

## 19.5 Inclusion and Exclusion Criteria

Inclusion criteria for the participation of patients included:

1. A diagnosis of advanced (NYHA III-IV) HF.

Exclusion criteria included:

1. Newly diagnosed patients who are receiving treatment for HF for the first time (i.e. patients within 6 months of first diagnosis of HF).
2. Patients who are not able to speak English

Patients who are newly diagnosed with HF were excluded from this study because these patients would not have had a chance to develop a relationship with the HF healthcare team. If this was a new diagnosis of HF, patients and family members are likely to be overwhelmed with information and it would be unethical to approach them regarding ACP research at this stage. Additionally, patients newly diagnosed with HF may not have experienced the type of complex health decision making that is characteristic of the advanced HF trajectory that was being explored in this study.

## 20 Data Collection Techniques

### 20.1 Case Studies and Data Collection

For the purpose of this research and in alignment with case study methodology, I used multiple data collection methods including semi-structured interviewing, document analysis and participant observation with field notes to highlight multiple facets of the ACP experience (Marshall & Rossman, 2010). Each of these methods will be further discussed based on their individual strengths and ability to contribute to this research.

### 20.2 Interviewing

Drawing on the tenets of feminist ethical theory, I placed the patient at the ‘centre’ of the case and interviewed relevant social influences such as spouses, family members, and professionals, in addition to examining the broader social and political structures that impacted the participants (Sprague, 2013). In order to examine the experience of people participating in ACP, one-hour,

tape-recorded dialogical interviews were conducted with seven patients, with interview invitations extended to spouses, family members, and relevant professionals, all of whom were identified by the patient, or by another participant of the study (see Appendix F for interview guide). These interviews were semi-structured in nature, and occasionally used important documents (i.e. Power of Attorney, Speak Up Advance Care Planning booklet, etc.) to initiate and stimulate discussion and support elicitation of perspectives and experiences. This type of interviewing using a feminist approach also allowed for theoretical perspectives to be integrated into the interview guide. As a critical researcher, I contributed to knowledge production through my interactions with study participants. With this view, participants were not revealing a solitary ‘truth’ regarding their experience, but instead expressing their current reality that had been shaped by values, ideas and power relationships (Lincoln & Guba, 2000). This reality is subject to change as participants have new experiences, and the interview is a site for the creation and generation of new knowledge that is shared between the researcher and the participant(s).

Documents were primarily identified and located through discussion with participants to explore what types of documentation they have utilized. Additionally, if participants had not utilized any documentation, documentation that was publicly available via the institution was drawn upon as a resource during interviews to stimulate discussion. This strategy allowed me to incorporate foundational aspects of relational autonomy into my data collection approach as I considered relevant relationships and documents as part of the case. This broad inclusion allowed me to capture the significance of both individual level relationships as well as broader, societal power-based relationships and how they influenced the experience of autonomy within the ACP process.

Interviews were held both at a location and time of the participant’s convenience; interviews primarily took place at a private room in the hospital, with two interviews being conducted at the participants’ homes. Before the start of the interview, I reminded participants of my professional background, reviewed the aims of the study and I thanked them for agreeing to participate. I then obtained written informed consent and reviewed the ethical protocol of the interview and explained the concept of process consent (i.e. Asking throughout the interview if the participant was willing to discuss various facets of ACP). Demographic information was collected in two ways; (1) a participant information sheet (see Appendix G: Participant Information Form) and (2) dialogically throughout the interview. This allowed participants to



maintain control over the information they chose to share, and also highlighted aspects of participants' identities that were most relevant to them. The collection of demographic data through dialogue allowed meaningful demographic knowledge to be discovered through conversation and unnecessary data collection was avoided (Morse, 2008). Interviews were recorded using an audio-recorder and were transcribed verbatim; language and grammar were not corrected. If participants were interested in meeting again, they had the option of additional follow-up interviews. This option was also available to family members and healthcare professionals, up to a maximum of two interviews with the same participant in order to maintain a manageable amount of data. Follow-up interviews took place either in person or on the telephone.

A semi-structured interview is a hybrid type of interview, which lies in between structured interviews and an in-depth interview (Wayhuni, 2012). This type of interviewing was beneficial because it allows the use of a list of predetermined themes and questions, while maintaining enough flexibility to allow the interviewee to discuss any topic brought up in interview (Wayhuni, 2012). The use of semi-structured qualitative interview is considered appropriate for case study research because this type of research seeks to better understand an experience in-depth within the real life context (Wayhuni, 2012).

## 20.3 Document Collection

Documents were sampled at both the individual patient level as well as at the institutional level. Documents such as existing living wills, ADs, POAPCs were collected if the patient was willing to provide copies of such documentation. This type of personal documentation was considered part of the individual level case. Educational information provided directly to patients was also collected, if and when relevant to the case. Documents from the wider institutional sphere included clinical practice guidelines or policy documents related to ACP, clinical or administrative documentation forms, e-learning modules for clinicians, pamphlets and online patient education documents. These documents were used to inform the analysis of cases through a discussion of the context of ACP within the institution. The analysis of these documents will be discussed later in this chapter.

## 20.4 Observation and Field Notes

Observation is a fundamental method in qualitative research which entails the systematic recording of events or behaviours in a certain social setting in which the participants function (Marshall & Rossman, 2010; Mulhall, 2002). Participant observation specifically was used as a technique in order to maintain firsthand involvement in the social world of the research and the study setting (Marshall & Rossman, 2010). Unstructured participant observation took the form of observing the patient's behavior and interactions within the interview setting, observing the patient and family within the waiting room or other public space, or participating in other activities with the patient or family, such as attending a lunch at an assisted living facility. All observation was limited to public spaces. This type of observation provided insight into interactions between dyads such as patients and their SDM and captured context or process that informed me about the influence of the physical environment on the participants being studied (Mulhall, 2002). During observation (when possible) and following all interviews I made detailed field notes, which were included in the analysis.

## 21 Methodological Rigour

As a critical researcher using a feminist perspective, I used of a number of criteria to achieve congruence between my research approach and methods for establishing rigour in qualitative health science research (Morrow, 2005). Therefore, in this study I drew on relevant criteria used to establish rigour in feminist qualitative research including researcher reflexivity, triangulation and transferability.

### 21.1 Reflexivity and Positionality of the Researcher

Case study explicitly supports a flexible and responsive relationship between the researcher and participants, which allows for enhanced examination of theoretical concepts in an empirical setting (Meyer, 2001; Sandelowski, 2011). As a registered nurse with several years of experience working with the cardiovascular population, it was important for me to examine my positionality in relation to the research topic and research participants (Dolye, 2013). I see myself as both an insider and outsider; I am a nurse with experience working with this population and am familiar with the process of ACP, however I do not have personal experience participating in ACP or

with living with chronic illness. As part of the reflexive process, it was my responsibility to examine the effect that my situatedness may have on the setting and the people being studied, as well as examine how my research question has been developed and what has influenced my interest (Berger, 2015).

It is clear that Western society values autonomy, and within healthcare systems the principle of autonomy is frequently given priority over other relevant bioethical principles such non-maleficence and justice. Being raised in this society and working in such an individualized healthcare system have influenced my interest in autonomy as well as my view that ACP has a role in chronic illness management from the perspective of healthcare providers. It is possible, and perhaps even likely that my participants did not share this viewpoint for any number of reasons, and therefore I was open to differing perspectives and ensured I was approaching interviews and engaging participants in a way that encouraged them to share their unique, and potentially converse perspective on this practice.

In qualitative research, the researcher is the primary tool for data collection and interpretation, and the behaviours of the researcher will always influence the direction of findings (Finlay, 2002). Using a critical perspective supports the idea of the researcher as a positioned moral agent within the research process, and suggests that research is a joint process involving the co-creation of knowledge (Finlay, 2002). Therefore, attending to the existence of power relations within the knowledge production process is necessary when considering that the researcher may be speaking for vulnerable groups (Sprague, 2013). As Suzanne Day (2012) suggests, by going deeper than merely declaring personal values and experiences and examining broader social contexts, I have considered the impact of power dynamics on the development of my questions and the role that power relations play in this research, which is especially relevant as I am using feminist theory.

This study has developed from the perspective of a healthcare professional who works with chronically ill patients and their families, which is a relationship with an inherent power imbalance. Therefore, it was imperative to acknowledge the influence of my positionality in relation to the research topic and participants, and maintain flexibility with my version of reality

(Dolye, 2013). Doyle (2013) suggests that authentic contact with both the other and the self is necessary for a reflexive research process, and therefore in order to promote rigour I developed a reflexive journal to document my perspectives as this project developed. The critical social paradigm also sees the researcher as a tool towards empowerment and advocacy (Lincoln & Guba, 2000). This goal resonates strongly with me personally and as a nurse because advocacy and empowerment are part of my professional responsibilities and moral obligations to my patients.

## 21.2 Triangulation

Case study also allows for triangulation of multiple data points. For the purposes of this study, Stake's conceptualization of triangulation was used, which suggests that triangulation allows for the championing of multiple perspectives, and helps to identify different realities rather than aiming to uncover a single truth (Stake, 2000). Coming from a critical perspective that views reality as mediated by power relationships, values and responsibilities, using triangulation in this fashion allowed for the privileging of multiple viewpoints in order to gain an in depth understanding of the power dynamics and various roles and responsibilities that influence complex social processes (Stake, 2000). The use of multiple sources of data is a hallmark of case study research and is also a strategy to enhance the credibility of the study (Baxter & Jack, 2008). I triangulated data collection techniques (i.e. through interviews, observations and document analysis) as well as triangulated sources by incorporating the perspectives of patients, family members, and healthcare providers in order to support the study's methodological rigour (Patton, 2002). As discussed by Baxter and Jack (p. 554, 2008), each data source can be viewed as one piece of a puzzle that enhances the researcher's understanding of the phenomenon as a whole, and study findings can be strengthened by "strands of data [being] braided together to promote a greater understanding of the case." Therefore, what participants report was not necessarily verified through triangulation, but allowed for a more nuanced and holistic understanding of the experience of ACP in HF.

Occasionally, the utilization and exploration of multiple data sources illuminated conflicting perspectives or views of reality. This is expected with critical research and provided deep insight into the value-mediated nature of reality that may be experienced differently based on social

location. This championing of multiple perspectives also aligned with the goals of critical research, which seeks to uncover assumptions and highlight the value-mediated nature of reality (Kincheloe & McLaren, 2000). This will be discussed further in the data analysis section.

## 21.3 Transferability

Transferability refers to the extent to which findings are useful to persons in other settings (Connelly, 2016; Polit & Beck, 2010). Transferability can be achieved by providing rich, detailed descriptions of the participants being studied and the context within which they are studied (Connelly, 2016). Transferability can also be achieved by providing sufficient information about the self (the researcher as instrument) and the research context, processes, participants, and researcher-participant relationships (Morrow, 2005). This information allows readers to decide how the findings may transfer to their unique setting or population (Morrow 2005). Transferability can also be enhanced by being transparent about data collection and analysis, and integrating theory throughout the research process in order to demonstrate how results may be applied in different settings (Connelly, 2016; Morrow, 2005). To support transferability, I maintained a small sample size in order to provide in-depth and detailed description of each case. I also kept a reflexive journal in order to report to readers my role as a research instrument in this process and developed a case study database to allow for data to be identified and traced through the study, providing an audit trail. Finally, as demonstrated, the theoretical perspective of relational autonomy was integrated at each stage of the research process, specifically and purposefully when analyzing the findings, to enhance credibility and potentially allow results to be transferred to other settings using the same theoretical perspective.

## 22 Analytic Approach

### 22.1 Critical Qualitative Analysis

As with much of qualitative research in bioethics, this topic is deeply grounded in philosophical theory yet seeks to construct knowledge through empirical data collection with human subjects. Feminist ethics has a history of using theory to explore ethical concerns in an empirical fashion, however there is a limited body of knowledge that uses relational conceptions of autonomy in

conjunction with empirical methodologies. Therefore, it was necessary to carefully consider all aspects of the data collection and analysis approach as well as be flexible and open to iterative change throughout the study. Jackson and Mazzei (2013) suggest using theory in conjunction with empirical data to achieve novel readings and analytic conclusions. Because of the ontological and epistemological standpoint from which I am working, it was imperative to avoid simplistic treatments of data, and instead incorporate the theoretical tenets of relational autonomy and feminist ethical theory through both the data collection and analysis processes (Jackson & Mazzei, 2013). As Ramazanoglu and Holland (2002) discuss, the researcher cannot set aside her perspective and life experience when interpreting research data, however using a theoretical framework and ensuring the political and ethical concern with power relations is the focus of the study ensured a feminist research process.

Feminists researchers conducting critical qualitative studies have critiqued a number of components of conventional qualitative research due to the objectification of research participants, the role of social power in the researcher-participant relationship, and the problematic assumptions some analytic approaches put forward (Sprague, 2016). Some strategies have been suggested in order to counter-act these concerns in the data analysis process (Sprague, 2016; Ramazangolu & Holland, 2002). One strategy is for the researcher to acknowledge “disagreement, inconsistencies and contradictions in data” in order to demonstrate the researcher’s positionality and approach to connecting experience with reality (Ramazangolu & Holland, 2002, p. 117). Additional strategies include using emotions as an analytic guide and using the researcher’s biography as a resource, both of which fall under the realm of employing reflexive thinking throughout the data collection and analysis process (Sprague, 2016). These strategies were employed consistently throughout the data analysis process in order to continually address the power dynamics and avoid perpetuating assumptions about the practice of ACP and the challenges with this process from the privileged perspective of a healthcare provider.

There is debate in the qualitative research field regarding whether or not to include the research participants in the data analysis process by “member checking,” or returning the data or drafts of analysis to the researched. Recently, critical feminists have come to view this process as more problematic than not, as it does not necessarily achieve the intended goals of compensating for

the researchers' privileged position, and also holds epistemological concerns when working from the perspective that knowledge is co-created throughout the research process (Sprague, 2016). Therefore, as opposed to using member checking, strategies such as drawing on alternative discourses and listening for alternative standpoints when analyzing data were included in my data analysis approach, in order to address these concerns (Sprague, 2016).

Overall, it is suggested that researchers continually “ground interpretations in experiences and interests” by working reflexively throughout the research process (Sprague, 2016 p.164). Researchers are accountable for the processes of data interpretation and the knowledge and understanding that is produced by these interpretations (Ramazangolu & Holland, 2002, p. 118). Feminist authors have suggested that by making the process of data analysis both political as well as intellectual, and by incorporating reflexivity throughout the process, feminists can navigate the unstable relationship between the researcher and the participants (Ramazangolu & Holland, 2002, p. 118).

Feminist thought also acknowledges the existence and effects of power relationships both within and outside of the healthcare context (Donchin, 2015). This means that feminist methods explore social structures and practices that are oppressive, and extend the examination of such power relations beyond the healthcare system to broader social arrangements that support longstanding patterns of domination (Donchin, 2015). Within this study, dominant social forces such as the power of biomedicine, neoliberal discourse, individualism and the primacy of legalistic understandings of autonomy were explored in relation to participants' experiences of decision making in ACP.

As mentioned in the introduction, I am defining ACP as an iterative process. Because it is always changing in relation to new health information, fluctuations in relationships and capacities, etc., it was important to accept that the data I collected was also incomplete and will always be part of a process of retelling and remembering (Jackson & Mazzei, 2013). The goal of my study was to begin to shift away from equating ACP to the presence of documentation (i.e. Power of Attorney for Personal Care) as the strong focus on documentation does not allow for the flexibility that is required of such a complex social process. I had to maintain this stance during data collection

and remember that the interviews, observations and documents I examined or analyzed represented only a small portion of the participants' reality.

## 22.2 Qualitative Data Analysis Using Relational Autonomy

To promote congruence between my theoretical perspective and my data analysis, I approached the data using feminist ethical theory and relational autonomy as the analytical lens. Relational autonomy informed multiple aspects of the study, including the use of case study methodology to gain access to different social influences on the experience of ACP, and supported the use of multiple sources and multiple data collection techniques. In keeping with relational conceptualizations of autonomy, a critical feminist lens was applied to the analysis phases of the case study research in order to explore power differences in the context of ACP. Using a case study analysis in conjunction with a critical feminist lens allowed power dynamics within social processes and relationships to be made visible so that they can be addressed (Sherwin, 1992; Mackenzie & Stoljar, 2000). Therefore, using the key concepts of relational autonomy, social location and medicalization in this study allowed for exploration of the social conditions and power differentials that exist for patients who are differentially situated in society.

In case study research, data from a variety of sources are analyzed together instead of examined individually, in order to provide a holistic understanding of a phenomenon and incorporate an exploration of relevant relationships (Baxter & Jack, 2008). This is another strategy that strengthens the findings of case study research by allowing findings to inform one another in order to more fully understand the case being studied (Baxter & Jack, 2008). As in the majority of qualitative research, data collection and analysis happen concurrently in an iterative fashion, in order for the inquiry to become more refined as data collection progresses (Baxter & Jack, 2008). Importantly, this study used relational autonomy as a theoretical perspective to provide descriptive clarity to the complex experience of ACP, as both theory and empirical data were used in an iterative analytical fashion. As Sherwin (1996b) notes, this type of feminist ethical inquiry does not strive to outline a set of eternal moral truths or provide strict normative claims, but seeks to highlight specific moral ideals that are relative to current context. By incorporating social, political and historical contexts into the analytical process, I was able to connect the practical experience of ACP as a moral experience with abstract theoretical proposals related to



relational conceptions of autonomy (Sherwin, 1996b). This type of feminist reflective equilibrium allowed me to question the constructions of the problems we study, in this case the principle of autonomy as an individualistic construct, and the influence of this dominant construct on current healthcare practice (Sherwin, 1996b). Employing this type of analysis also achieved the goals of critical and emancipatory research by ensuring that I was attentive to the ways that my own moral values reflect current political systems and that I did not use abstract conceptual frameworks to perpetuate systemic injustice (Sherwin, 1996b).

## 22.3 Case Study Analysis

Alongside the analytical framework of relational autonomy, case study analysis was employed in order to identify aspects of the ACP experience that may be common across cases or unique to an individual case. Using the principles of both within-case and cross-case analysis (Ayres, Kavanaugh & Knafl, 2003), I first considered each case as a whole. I constructed each case starting with the individual patient and working outwards to include individual level relationships with family members and professionals. I will also examined the role of broader societal relationships using the concept of social location. Once each case was constructed and analyzed, a cross-case analysis followed, where patterns, or similarities, as well inconsistencies across the various cases were identified and explored (Ritchie et al., 2003; Ritchie, Lewis, Nicholls & Ormston, 2013; Patton, 2002; Spencer, Ritchie & O'Connor, 2003). As opposed to searching to uncover one singular or central truth, my goal was to examine how autonomy is experienced relationally, and how ACP may be approached differently based on patients' social location.

## 22.4 Coding Strategies

Both interview transcripts and observational field notes were coded in order to develop specific categories of analysis (Morse & Richard, 2002). NVivo 11 software was used to manage the data and facilitate coding throughout the analysis. Preliminary coding categories were derived directly from transcripts and field notes using qualitative content analysis (Hsieh & Shannon, 2005; Shreir, 2014). Using this type of data-driven approach allowed for relevant themes to be derived directly from the data and counteracted the danger of analyzing the material only through the lens of one's own assumptions or expectations (Shreir, 2014). Therefore, codes were

developed using an iterative process of constant comparison both within and across cases. These codes were altered and refined in an iterative fashion once data analysis had begun.

Through several rounds of coding, I moved between the empirical data and emerging analytical concepts. Both inductive and deductive analytic techniques were used in order to interpret the study data (Reichertz, 2014). The first rounds of coding progressed inductively and were grounded in terminology employed by participants themselves (Elo & Kyngas, 2008; Reichertz, 2014). This early coding sought to engage with the data at a general level and develop initial analytic ideas. Further analysis utilized a deductive approach to examine tensions within data, with specific attention to the relationship between the participants experience and the key documents being analyzed. Both methods were beneficial as deductive analysis can be used to better understand existing knowledge in a new context (Elo & Kyngas, 2008; Reichertz, 2014), whereas inductive analysis is used when there is dearth of existing knowledge about the phenomenon of interest (Elo & Kyngas, 2008; Reichertz, 2014).

Data collection and analysis occurred simultaneously to allow emerging ideas to be explored in subsequent interviews (Morse & Richard, 2002; Patton, 2002). Analysis meetings were held to discuss coding strategy, analytic ideas and findings with the research team. The theoretical framework and key concepts of relational autonomy, social location and medicalization were integrated throughout both the data collection and analysis process (Jackson & Mazzei, 2011). Moving between the data and the concepts central to relational autonomy and feminist bioethics allowed for deeper theorization while use of key concepts supported the analysis (Peter & Friedland, 2017). Reflective equilibrium was employed as an established analytic method in bioethics in conjunction with case study analysis, which involved identifying a set of moral judgments about a group of cases, identifying relevant values or principles that relate to the cases, exploring how these values fit in cases with contextual differences and then revising these values to achieve coherence (Sherwin, 1996b; Gibson et al., 2012). This analysis was based on the priorities, understandings and experiences of the people involved in the case study, and moved both “upwards” from data to theory, as well as “downwards” from theory to data, in an iterative fashion (Gibson et al., 2012). As the primary researcher I was immersed in the data through both the collection and analysis phases, and moved between the data collected, the research questions and the theoretical framework in order to develop relevant themes (Peter &

Friedland, 2017).

## 22.5 Document Analysis

Documents can be thought of as physical evidence of social settings and as such provide a mechanism for understanding social and organizational practices (Coffey, 2014). Documents were analyzed not only for their content, but also to better understand the circumstances under which such documents were created (Coffey, 2014). This type of analysis recognizes that documents themselves are ways that social actors make sense of the social world and are rarely produced in isolation from other texts (Coffey, 2014). Therefore, this analysis included an examination of what language is used in such documents, what the purpose is of each document and the relationships that are present both within an individual document and across documents (Coffey, 2014). Deeply engaging with not only the documents, but also the processes that take place around specific documentation may provide more information regarding the complex relationships and power dynamics that are at play when trying to make future healthcare decisions. As mentioned, an examination of the tensions between participants' experiences, the role of the documents in shaping these experiences and the assumptions that existed within the documents was a key component of the final stages of the analysis. The theoretical framework of relational autonomy, as well as social location and medicalization as key concepts also guided the analysis of these documents and was incorporated throughout the coding and analytic process. Overall, documents were explored to better understand not only their relevant content, but also their effects on social discourse related to ACP and how they influence or are influenced by dominant power relationships.

## 23 Ethical Considerations

### 23.1 Risks and Benefits

There was a low level of risk present for all participants in this study based on the University of Toronto's research ethics board risk matrix (University of Toronto, n.d.). For HF patients and their family members, there was a risk of becoming emotionally distressed during the interview due to the nature of the questions and the discussion of past illness experiences, experiences making healthcare decisions or participating in ACP. As a registered nurse with several years of

clinical experience with this population as well as previous experience conducting qualitative interviews on this topic, I had the ability to identify emotional distress. If participants became distressed, I paused the interview and as a healthcare professional I provided in the moment support and then asked permission to continue the interview, if appropriate. If participants did not want to continue the interview, I would ask permission to return to the interview on another day. If participants became acutely distressed, I planned to notify the referring HF team member(s) and the participant to be referred for psychosocial support at the institution. Fortunately, during the course of the study recruitment and interview process, no participants became acutely distressed. There were however multiple occasions where participants demonstrated some emotional distress, and interviews were occasionally briefly paused, however all participants wished to continue the interview. These emotional moments were also highly important in the analytical process, as this aspect of ACP is something that is not often directly addressed in the current literature.

If participants were not able to participate in extended interviews, there were options for shorter, multiple interviews in person or interviews done over the phone. For interviews conducted in the home, if the patient became acutely ill, I planned to contact the HF clinic or other emergency services if necessary; fortunately, this was not necessary. Direct patient care was not to be provided to participants by the researcher during interview sessions nor in the future if patients were admitted to the hospital setting, in order to prevent undue influence of participants. In order to achieve this, the Manager and Patient Care Coordinator of my workplace were informed of the nature of the study, the potential for conflict of interest and the need to have flexibility in patient assignment. Due to my position as a casual employee and the small sample size of this study, I did not anticipate a significant risk of this occurring, and fortunately it was not a concern. Patients that I had cared for previously in my role as a registered nurse were excluded from the study in order to prevent undue influence of participants to consent to participate in the study.

Potential benefits to participants included the interview being a confidential and safe environment to speak about experiences and tell illness narratives. Joint interviews with multiple family members allowed the opportunity for increased communication between family members, which could be beneficial to all parties involved. Participants may have derived

therapeutic benefit through the interview by potentially encouraging further patient-family conversation regarding ACP. Interviews may have also helped patients identify ways that participating in ACP could be beneficial to them. Finally, there is well-established research on the altruistic benefit that patients experience when participating in research, specifically in palliative and EOL care literature (Wright & Flemons, 2002; Fitzsimons & Strachan, 2012). The benefits of this research to future patients have been previously discussed. This study provides knowledge of the relationships and wider institutional and social discourses that influence the ACP experience for HF patients and their families. This knowledge can direct us to develop better ACP interventions and support patients and families as they navigate challenging decisions throughout the HF trajectory.

For healthcare providers there was also a potential risk of becoming distressed related to questions regarding ACP or working with patients living with a life-threatening illness, however none of the healthcare provider participants experienced distress during the interview process. Potential risks may have also included disclosing information that violates professional practice standards. Any such violation must be reported to the relevant professional's regulatory body, such as the College of Nurses of Ontario; fortunately, this measure was not necessary in any of the cases recruited. Potential benefits to healthcare provider participants included the opportunity to discuss ACP and debrief potentially challenging situations that providers encountered surrounding the ACP process.

## 23.2 Confidentiality

Participation in this research project was voluntary and confidential. Written consent was obtained in order to interview or observe participants as well as examine any documents that are personal in nature (i.e. POAPC documentation, living wills, advance care directives, etc.). The participants provided any relevant documentation to the researcher; they were not extracted from the medical chart. As the goal of this project was to understand the process of ACP from the perspective of the patient, medical records were not accessed or analyzed. Identifying information was left out when examining and analyzing documents. Participants were assigned a numerical identifier that was used to organize all data; any identifiable details in audio recordings were not transcribed and any identifiable details found in documents were removed

from copies of documentation. Pseudonyms were given in order to construct each case using names, and any identifiable details were altered in order to present a case that closely resembles the original but does not allow for identification of participants. Audio files were deleted after transcription and analysis. No information that would disclose personal identity will be released or printed, and direct quotations were reported using a pseudonym. All consent forms were kept in a locked filing cabinet, in the double-locked office of the researcher at the main study site. All transcribed data was kept on a secure computer and protected by passwords only known to the researcher. Digital audio files were coded to eliminate identifying information and stored in a password-protected computer on a secure server. Only the researcher and the committee had access to the data, and the researcher will keep the data of the study for seven years and will then dispose of all research material in a secure and confidential fashion. This study was approved by the Research Ethics Boards at both Hospital Centre A and Hospital Centre B, and was also approved through the University of Toronto Health Sciences Research Ethics Board.

## Chapter 5

### Introduction to Results

This introduction to the results will take the following format: first, an overview of each case and a description of the relevant participants will be presented. Following this, excerpts from the case study database will illustrate the demographics of the participants and the data sources sampled in this study in order to provide contextual grounding for the interpretation of results. Finally, a brief conclusion will outline the following three chapters of the results.

### 23.3 Overview of Cases

#### 23.3.1 Case 1: Nathan (Hospital Centre A)

Nathan was a middle-aged, white Canadian male, with a long history of HF who had received a heart transplant 6 months prior to our interview. Nathan worked as an engineer and was married to Tracey, a registered nurse who worked in an acute care setting outside of Toronto, and together they had two children who were both either studying or working in the healthcare field. I interviewed Nathan along with his daughter Sarah about their experiences and had a follow-up interview with Nathan's wife Tracey, who had a unique perspective as she was simultaneously an experienced healthcare provider and a family member. Nathan had experienced a number of serious medical complications both pre- and post-transplant that shaped his understanding of ACP and decision making.

Expanding outwards to construct this case, I interviewed Betty who was one of the allied health professionals who worked with Nathan and his family and who worked with many transplant patients from a variety of transplant programs. Kate, a palliative care provider who worked with the transplant and LVAD population, was also interviewed. This case also included an analysis of the transplant education material provided by Hospital Centre A, as well as the institutional policy on Advance Care Planning which was relevant to Nathan's experience.

#### 23.3.2 Case 2: Alvita (Hospital Centre A)

Case 2 was constructed around Alvita, who was an 87-year-old black woman originally from the Caribbean Islands who had a more recent diagnosis of HF and was new to the heart function clinic at Hospital Centre A. Alvita did not have post-secondary education, she had worked all her life in a variety of administrative and office jobs, and raised her family primarily independently; at the time of the interview she had been a widow for a number of years. Although she had 4 children, Alvita's healthcare was primarily managed by her two daughters, Gabrielle and Brianna, who were both registered nurses. Gabrielle and Brianna were included in the interview process as they supported their mother's healthcare needs, but at the same time Alvita considered herself quite independent as she still lived in her own home and attended community centre activities. Alvita also loved to volunteer, shop and travel, however she had recently limited these activities due to her increasing HF symptoms. This case also included an analysis of an institutional living will brochure that was relevant to Alvita's experience.

### 23.3.3 Case 3: Peter (Hospital Centre B)

Peter was a 74-year-old white Canadian male who was married with 3 children and had a long and extensive history of cardiovascular disease. Peter had an undergraduate degree in engineering, however worked all his life as a contractor and carpenter, primarily in rural Ontario. At the time of recruitment, he was living with end-stage HF. He was extremely frail, and after being seen at a routine clinic visit at Hospital Centre B, was admitted by his cardiologist to Hospital Centre A for management. I interviewed him during this admission, as he was in the process of being worked-up for a MitraClip® procedure to improve his symptom burden. I attempted to conduct a second follow-up interview with him, however, he was too fatigued to participate. The healthcare team did move forward with the MitraClip® procedure, however, the procedure had to be aborted due to a change in clinical status, and shortly thereafter Peter experienced a cardiac arrest. The team attempted resuscitation, but Peter died in Hospital Centre A.

Case 3 also included an interview with Rose, an allied health professional who was helping to manage Peter's care, as well as an interview with Daniel, one of his treating cardiologists. Finally, this case also included an analysis of the Informed Consent for Resuscitation Policy



from Hospital Centre A as this was something that influenced Peter's care and the role Rose played in his experience.

### 23.3.4 Case 4: Diane (Hospital Centre B)

Case 4 was focused on Diane, a 98-year-old white woman, who was originally from Austria and now lived in an assisted living facility in downtown Toronto as she was a widow with no children. She had been a teacher all her life, her husband had died a number of years ago. She had a longstanding diagnosis of HF with preserved ejection fraction and was relatively stable symptomatically. Despite this, she had other health issues that impacted her quality of life such as chronic pain as well as hematological and oncological concerns. Diane had a niece who lived in the United States who was her only living family member and was the person who supported her health decision making and managed her financial affairs. She also had hired personal support workers to help her when she had to attend her many medical appointments. Otherwise Diane was relatively independent and was able to host me for an interview at her apartment at the assisted living facility where I visited her apartment and we had lunch.

This case also included an interview with Andrea, a registered nurse in a leadership position at the assisted living facility, as well as Greg, Diane's family physician who worked with many aging patients in the community. Finally, this case also included an analysis of the Intake Assessment Form used at the assisted living facility which guided healthcare decision making and was where healthcare staff documented important decisions related to the patients' management.

### 23.3.5 Case 5: Han (Hospital Centre A)

Han was the patient who was the focus of Case 5. He was a 65-year-old Asian male originally from China, who was married with two children. Han was an electrician by background but was now retired and lived comfortably in the suburbs of Toronto with his wife. Han's HF had advanced to the point that he was being worked-up for a heart transplantation. Throughout my time with Han, he was working through the process of deciding whether or not he would like to move forward with accepting the transplant. This case consisted of an initial interview with Han and a longer follow-up interview with both Han and his wife. Additionally, this case included an

interview with Marie, Han's transplant cardiologist and Christopher, an allied health professional at Hospital Centre A. Finally, this case also included an analysis of the documents provided to transplant patients as part of the standard work-up: the Speak Up booklet and the Power of Attorney for Personal Care document from the Ontario Ministry of Health.

### **23.3.6 Case 6: Marty (Hospital Centre B)**

Case 6 focused on Marty, who was an 88-year-old white Canadian male. Marty was married to his wife Brenda with three children, he had worked in the sales and insurance industry his entire life and lived comfortably in his family home in the suburbs of Toronto. Marty and Brenda hosted me for an interview at their home in west Toronto. Marty had a longstanding diagnosis of HF and in the past few years had received an implantable cardiac device and had experienced a few significant exacerbations requiring intensive care unit admissions. Marty also had a history of prostate cancer. Marty was an extremely social person who had been very active within his community, which shaped his experiences. Because he was followed at the Heart Function clinic at Hospital Centre B, Case 6 also included an analysis of the Consent to Treatment policy for this institution as he had provided consent to receive an implantable cardiac device, as well as an interview with Judy who was an allied health professional from the Heart Function clinic who worked with him.

### **23.3.7 Case 7: Pam (Hospital Centre A)**

Finally, Case 7 was centered around Pam, who was a 60-year-old white Canadian woman with Mediterranean heritage. Pam had a relatively new diagnosis of HF that may have been caused by previous chemotherapy. Pam was a married mother of four and also a new grandmother, and she was well supported primarily by her two daughters who accompanied her to medical appointments. Pam's husband and children ran a business together, and Pam had attended university, however, once she began to have children she was their primary caretaker and did not work with the business or outside of the home. Pam's family lived comfortably in the suburbs of Toronto, and her children all lived nearby. Our interview involved both Pam and her eldest daughter, Katharine. Pam's history of breast cancer also shaped her understanding of illness and experience with HF and ACP. Case 7 also included an interview with Sheena, who was an allied

health professional with a background in ethics and law who was rotating through Hospital Centre A at the time of Pam's recruitment.

## 23.4 Case Study Database

The following case excerpts from the case study database will provide an overview of the range of characteristics of the participants and data included in this study. The purpose of the case study database is to demonstrate the specific make-up of each case, the variety of participants and data sources drawn upon, and the way that data was recruited and sampled as it relates to each case (Yin, 2009). The table outlines the ways that data were identified and recruited into the study, however, many participants (i.e. HCP) and documents (i.e. organizational policies) informed more than the one case to which they are attributed.

Table 2: Overview of Demographics

Case	Pseudonyms	M/F	Age	Country of Origin	Family Status	Additional Participants / Interviews	Documents
1	Nathan Tracey Sarah Betty Kate	M	56	Canada	Married + 2 adult children	Daughter Wife Social Worker Palliative Care Physician	Transplant education book Resuscitation Policy Advance Care Planning Policy
2	Alvita Gabrielle Brianna	F	87	Caribbean Islands	Widowed + 4 adult children	Daughters x 2	Living will document
3	Peter Rose Daniel	M	79	Canada	Married + 2 adult children	Nurse Practitioner Cardiologist	Informed consent for resuscitation policy
4	Diane Andrea Greg	F	98	Austria	Widowed, no children	Registered Nurse Family Physician	Intake assessment form
5	Han Lily Marie Christopher	M	64	China	Married + 2 children	Wife Cardiologist Bioethicist	Speak Up Booklet Power of Attorney for Personal Care Document
6	Marty Brenda Judy	M	88	Canada	Married + 3 children	Wife Nurse Practitioner	Institutional Consent Policy
7	Pam Katharine Sheena	F	60	Canada	Married + 4 children	Daughter Bioethics Fellow	

Table 3: Overview of Total Data Sources

Case	Participants	Interviews	Documents	Observational Notes	Total	Pages of data
1	5	4	1	2	12	132
2	3	1	1	1	6	54
3	3	3	3	1	10	69
4	3	3	1	1	8	61
5	4	4	2	1	9	91
6	3	2	1	2	8	65
7	3	2	0	1	4	36
Contextual			2			29
Totals	24	19	11	9		537

## 23.5 Conclusion of Introduction to Results

Together, these cases highlight the diversity of experiences of living with HF and the variety of complex trajectories that can accompany this disease. In the following sections, I will reintroduce key theoretical ideas from feminist ethics and relational autonomy while examining the participants' stories in relation to each research question and the goals of the study. The first chapter will answer the research question: "how do people living with heart failure understand advance care planning?" by providing a description of the field of ACP in advanced HF. This chapter will outline the variety of ways people understand ACP within the context of advanced HF, with a specific focus on medicalization and the primacy of the legal model. The second chapter will begin to answer the research question: "how do people living with heart failure express autonomy when participating in advance care planning?" by examining the ways that people experience choice and decision making when living with HF. This chapter will expose the incongruence between the traditional model individual autonomy (the dominant construct that underpins ACP in this setting) and the experiences shared by participants that are centered on relationships and responsibilities. The third and final chapter will respond to the research question "how is heart failure patients' experience of autonomy and participation in ACP mediated by their social location?" by demonstrating the relational reality of living with advanced HF and outlining the variety of ways that autonomy is shaped by interpersonal relationships, social location and broad social forces.

## Chapter 6

### Results 1: ACP in Advanced HF

#### 24 A Description of the Field: ACP in Advanced HF

As described in the methodology chapter, participants in this study were recruited from two study sites. An overview of the characteristics of these sites and the respective clinic populations can be found in Chapter 4. The broader social field and institutional cultures of both settings impacted all of the cases recruited for this study, therefore, a brief overview of the social setting will be provided in order to ground the results in this social context.

Participants were recruited from outpatient heart function clinics at two downtown academic health centres: Hospital Centre A and Hospital Centre B. These centres are in close physical proximity but serve distinct roles and have different client populations. Hospital Centre A is a specialized cardiac centre, and socially, this centre is viewed as a “mecca” or temple of cardiovascular care, that provides care to patients with complex and exceptional illness. The institution also propagates this message through various methods of advertisements, campaigns and social media. For example, their website homepage describes the cardiac centre as a “world leader” in cardiovascular care and accentuates the “game-changing research” and “live-saving devices” they offer. This website frequently highlights stories about patients receiving intensive therapies and advanced devices, with headlines such as “Nothing to Lose and Everything to Gain”, a story reporting on a patient who received a LVAD device. Finally, the social media pages for this centre are frequently reference statistics that highlight the high ranking of the facility, both nationally and internationally. This overwhelming sense of reverence was captured by Rose (HCP, Case 3), a nurse practitioner in the cardiac program who highlighted the institution’s role in perpetuating this discourse by stating: “it’s what we [as a cardiac centre] do too, right?” She described how Hospital Centre A is known for its “complicated cases” and that there is always “more and more technology and techniques available” that shape the expectations and experiences of both healthcare providers as well as patients and families who receive care at this institution.

In comparison, Hospital Centre B serves an older demographic of patients who have less complex HF but are often living with additional co-morbidities usually related to frailty or advanced age. These patients are not usually candidates for advanced therapies. Despite this, patients may be referred from Hospital Centre B to Hospital Centre A for specialized non-invasive therapies such as TAVI or MitraClip® procedures. Together, Hospital Centre A and B work together to meet the needs of the growing HF population. This was highlighted by Daniel (HCP, Case 3), who worked at both settings but primarily out of Hospital Centre B, when he discussed how his clinic was a “feeder hospital from Hospital Centre A” which meant that he received patients who were “older and...not likely to be candidates for more advanced HF therapies”. The following section will describe the social setting of HF care in urban Canada from the perspectives of the participants in this study in order to provide the context necessary to facilitate interpretation of the results of this research. This chapter will examine the influence of both the biomedical model and the legal model on the process of ACP, and will conclude with an examination of the way that ACP has been reduced to a process of legal documentation in order to answer the question: how do people living with HF understand and approach advance care planning?

## 24.1 HF-ACP is Shaped by Biomedical Individualism

The biomedical model promotes medical individualism by dedicating specific treatments to specific patients based on individual pathologies (Sherwin, 1998a). In this study, participants often framed their understanding of HF through the biomedical treatments and interventions that were available, as well as the relevant candidacy criteria and evidence-based guidelines. Because of the high level of medicalization, and the vast array of technology available to treat HF in the current healthcare system, the socially and morally acceptable path presented to patients was to pursue treatment and “fight” their disease (Tracey, Nathan’s wife, Case 1). In this framework, biomedical treatments were seen as benevolent measures taken towards improving individual health (Morgan, 1998). Therefore, accepting advanced and invasive treatment was often presented as the only path available, even for patients in this study who were at a very advanced or end stage of the chronic and terminal disease that is heart failure.



## 24.2 The Benevolence of Biomedicine: Positive Constructions of Technology, Science, & Intervention

Participants praised the achievements of biomedicine and revered the information that was obtained from the highly technical care provided by the heart function clinics and hospitals. Nathan and Marty understood biomedical expertise as the ability to gather information by performing many tests (i.e. blood work, x-rays, CT scans, ECG, pacemaker reports, etc.) and then “make decisions” or “dictate what is going on” to the patient:

“It’s amazing here [Hospital Centre A]. They’ve got everything here that you need. They have got all the teams, and they make decisions and do the tests when they need to do them. It doesn’t matter what it is. Like I have said many times, I cough and there will be blood work and they will do an x-ray on my chest and then a CT scan of my chest and then make sure that three or four other things are okay.”

Nathan (Patient, Case 1)

“I think the world of Dr. McMillan [cardiologist] - he is so precise about everything he does. He takes such good time at looking at what has happened, what the results of the blood lab brings, what the ECG brings, what the pacemaker brings and so on, so forth and then dictates what he is going to do or suggest and says do you agree? He’s wonderful. He’s wonderful.”

Marty (Patient, Case 6)

Nathan and Marty discussed how they appreciated the ability to have multiple tests performed using an array of technology, and they connected the availability of biomedical technology to the expertise of HCP in making decisions and suggesting care plans. They viewed the ability to examine data from multiple biomedical sources as a highly skilled endeavour that allow them to receive the best care possible. Similarly, although Han (Patient, Case 5) recognized the risk of death that accompanies a heart transplant procedure and was wary of taking this risk, he expressed that he could not “oppose” the suggestion of a transplant on the basis of poor technology. He also presented a benevolent view of biomedical treatment by acknowledging that if he died, he could only blame his “bad luck” and could not blame technology because it is “all there”. This exemplifies medicalization as defined by Morgan (1998) in which medical authorities exercise the highest level of control over medical knowledge, and treatments are seen as the only (or the most) legitimate method to control the medically defined problem. Even though Han was not confident that receiving a heart transplant aligned with his personal

assessment of his quality of life, he was struggling with this decision; it seemed impossible to argue with the proposal of a transplant as it was the most “legitimate method to control the medically defined problem” of having HF (Morgan 1998).

In comparison, Daniel (HCP, Case 3) and Rose (HCP, Case 3) discussed the highly technical nature of current HF care which led to very complex decision making. Rose (HCP, Case 3) described how Hospital Centre A tended to perpetuate the stereotype that they could “do anything” and that there was an endless push for more technology as an institutional culture. She acknowledged that the availability of these technologies combined with the benevolence of healthcare providers who “always want to help” can shape the pathways provided to people to navigate through their treatment. Daniel (HCP, Case 3) went on to outline the vast variety of therapeutic options and technologies now available for people living with HF, and the number of decisions that must be made:

“Well, I think they [patients] have to decide what level of intervention they are going to want. We have all kinds of tools and even non-invasive tools that we can use now in 2018: things like putting PA catheters and implantable devices in, doing tricuspid or mitral interventions without surgery, doing aortic valve interventions without surgery. And then the medical therapy and the intensity of their follow up, whether they want to come in, whether they want to be seen at home, there’s lots of decisions to be made and every decision kind of has some sub decisions. For example, if somebody decides they would be okay with having a Mitra-Clip then they also would have to decide whether they want to come in for all of the investigations that would be required beforehand and do they have transportation, is this something they want to spend their time doing?”

Daniel (HCP, Case 3)

Here, Daniel used the example of the MitraClip® procedure to explain the variety of decisions that must be made. This can be related to the experience of Peter (Case 3) a patient who was having “all of the investigations that would be required” to determine if he was a candidate for the MitraClip® procedure. Despite the way Daniel outlined the variety of decisions and sub-decisions available to patients, Peter expressed that he had “no choice” regarding this procedure or the requisite work-up, and it was unclear whether this would be how he would have “chosen” to spend his time. Daniel provided a more measured assessment of technology that was not necessarily benevolent, as he identified that patients must carefully consider whether this is something that they “want to spend their time doing”.

This demonstrates Morgan's (1998) concept of "medicalized agency" (p. 96) in which patients are constructed and experience themselves as medicalized subjects leading to medicalized self-management. This medicalization of HF patients supports Daniel's rhetoric of responsibility, control, and self-determination (Morgan, 1998), as he constructed his patients as people with highly developed agency who can decide whether pursuing biomedical treatment is "something they want to spend their time doing," despite the fact that they may not have been presented with any other options.

### 24.3 The Multiple Meanings of "Aggressive" Treatment

The concept of aggressive treatment was brought up by patients, family members and healthcare providers. Patients and caregivers perceived aggressive treatment as a positive, as something that was both intense and productive and achieved the desired results of improving health outcomes, as highlighted by Brenda, Marty's wife:

"I personally found that Dr. Rogers was not as aggressive as Dr. McMillan with medications, from one doctor to another cardiologist. And because of his aggressiveness, Dr. McMillan, he [Marty] came around. There was some point after he got the heart failure when he was sent to downtown for a consult, and then when he started to feel a little bit better he brought up several times that maybe we could just get referred back to Dr. Rogers. And I said "Marty, just zip up!" {Laughing} I says "I have faith in Dr. McMillan. He is aggressive in the way he treats, although Dr. Rogers is good too.""

Brenda (Marty's wife, Case 6)

Dr. McMillan's "aggressiveness" improved Marty's health. In comparison, HCP use "aggressive" in a variety of ways, but most often "aggressive treatment" is a synonym for "futile treatment." Kate (HCP, Case 1) expressed frustration with "aggressive care" where "we crack open their chest and are changing their lungs," understanding this type of aggressive treatment as often futile in end-stage disease. She also expressed how the limited language of "do not resuscitate" did not cover the range of aggressive treatments that can be offered to people, often leading them to receive aggressive measures that may or may not be beneficial. This discrepancy between understanding "aggressive" as something positive and productive compared to something negative and futile may contribute to the conflict or miscommunication that occurs with patients and families when they are portrayed as "requesting" aggressive treatment that is distressing to HCPs who view aggressive as treatment that has no therapeutic benefit.

## 25 Biomedicine Cannot Provide a Complete Account of the HF Experience

Despite the benevolent view of biomedicine and medical treatments, participants simultaneously experienced the harsh limits of medical technology and the reality of their constrained autonomy. Heart failure is complex and response to treatment was often uncertain. There were limits to the data available to make decisions in the advanced stages, and HCP still viewed patients dying or requiring palliative care to be a personal failure or a sign that they had “given up” (Daniel, HCP, Case 3). This combination of complex disease, uncertain treatment course, and limited data along with providers’ aversion to palliative care led to a failure to acknowledge the terminal nature of the disease and a certain avoidance of conversations related to ACP more broadly.

### 25.1 Alas, Biomedicine Cannot Fix Everything

Rose (HCP, Case 3) and Tracey (Nathan’s wife, Case 1) highlighted their frustration with the biomedical system’s sole focus on fixing disease states. Rose discussed how the team was focused on “planning for the MitraClip® procedure” for her patient, Peter (Case 3), which was seen as a temporary fix that would have allowed for further medical management and also would have acted as a distraction from the fact that Peter was living with an advanced terminal illness. Rose experienced the tension between being obligated to work towards a technological “fix” for Peter’s disease, while at the same time understanding that he was quite sick and frail. She also seemed to recognize that Peter and his family may not have realized that he was nearing the EOL because the focus on the MitraClip® procedure allowed them to ignore his advanced illness state:

“Because his wife is the main care provider for him, and last week I asked them if they had a conversation [regarding resuscitation] because he is in the hospital and it’s not something they feel comfortable just talking about on the phone. I guess my assumption is they are just still planning for procedure, even though we mentioned that mainly it’s more for symptom control. Having that fix we may be able to, you know, titrate the medication - it’s to have easier diuresis. But on the other hand, you wonder how much they really absorb, truly understand right?”

Rose (HCP, Case 3)

As a caregiver of someone who had been quite ill, Tracey recalled her annoyance that HCP wanted to focus on fixing her husband without making a holistic plan and acknowledging the bigger picture of his overall disease state:

“So, everyone wanted him to live. They kept trying to fix him instead of making a plan on how to move forward and deal with this. Like they kept saying “oh yeah, you will live to 75 you know. This usually blows down right about the age you are...it shouldn’t be much of a problem anymore, you have kind of peaked and here you are.” Well, no. Like I said, I think it’s so important, and having lived the life of a heart failure patient either a) at work or b) at home it is a terminal disease and people need to realize that we can’t fix everything and people are not going to live forever and I think we need to be a little more clear about that.”

Tracey (Nathan’s wife, Case 1)

As both a family member and a nurse, Tracey knew that “we can’t fix everyone” and highlighted the need for HCP to acknowledge that HF is a terminal disease, despite the offerings that biomedical technology can provide. As van Heijst (2009) notes: “advances in biomedical technology provide almost unlimited possibilities, and cultural expectations regarding medicine are high” (p. 201). These powerful social and cultural expectations encourage professionals to do all they can, even forcing “diagnostic and therapeutic interventions upon people who have little or no chance to recover” (p. 201). This is clearly demonstrated in Peter’s experience of receiving the MitraClip® procedure despite the fact that he had little chance of recovery, Marty receiving a CRT-P despite having a DNR in place, and Nathan’s experience of “everyone wanting him to live” without addressing his mortality. This unilateral focus on saving lives may render professionals oblivious to the needs of patients who cannot be cured, and who may require or benefit from different types of support (van Heijst, 2009).

## 25.2 Palliative Care as the Failure of Biomedicine

In this study, palliative care was often constructed by HCP as a failure of biomedicine, in that it would only be offered to patients once there was nothing further that could be provided in terms of active biomedical management. Palliative care was seen as something that was employed when the clinical team no longer had a plan or were not in control of what they were going to do next. Despite recognition and understanding that palliative care should be offered concurrently with active HF management, in some cases HCP working with HF patients were unable to initiate this service. Palliative care referrals functioned as a signal to other HCP that the treating

team had “given up” (Daniel, HCP, Case 3), and Daniel highlighted how he did not want other HCP to think he had given up on his patients, which is why he avoided a palliative care referral despite full knowledge of the benefits of the service:

“You know, there’s still this dichotomy in cardiology that palliative care is something that’s reserved for people that you have nothing else to offer, but the truth is just like in oncology it should be done concurrently. Like we have one patient who is like really toeing the line of not being transplantable and she’s 51 and I don’t think we’ve ever had palliative care see her. Both me and Dr. Yung were on for the weekend and both of us were trying to get her through to the transplant and that’s been our focus. Like is she going to be transplantable, is she not and, and yeah, the very notion of getting her to see palliative care probably turns both of our stomachs, even though it’s probably the right thing to do. Just because we really want her transplanted. Anyhow it’s like there is still this element, even though we both understand what palliative care is, that once we refer to palliative care that we have given up, which we haven’t, and so we want to be very clear that we haven’t.”

Daniel (HCP, Case 3)

Even for providers from outside of cardiology, such as Greg (HCP, Case 4), there was an understanding that palliative care is only involved when death is imminent.

Tieghan: Okay and is there much discussion around palliative care or EOL planning?

Greg: Only when you get to that point. Don’t discuss palliative care unless they are really palliative. But sure, when we get to that point, yes.

(Case 4)

Rose (HCP, Case 3) also echoed this sentiment:

Tieghan: Do you end up bringing them [palliative care] in sometimes?

Rose: That depends, like if we definitely think there’s nothing else that can be done, just medical management for the symptoms. Completely symptom control.

(Case 3)

Kate (HCP, Case 1), a palliative care provider described how she often received referrals for patients because the “patients aren’t rebounding from their exacerbations as well and the team struggles with what they are going to do next”. Because ACP is often part of the provision of palliative care, this may contribute to why ACP is so challenging to implement in the HF population specifically. Unlike many other types of referrals (i.e. initiating a referral for a HF patient to be seen by a nephrologist to address kidney function issues), referrals to palliative care were not based on patient need or prognosis, but were rather constructed as the only option left

for providers who didn't know what to do, or what else to offer, or had "given up". In this construction, it is clear why HCPs working in cardiovascular care may delay referrals to PC, as it is seen as a failure of their medical expertise and is only relevant once they have exhausted every possible biomedical treatment option available to the patient.

## 26 ACP is Understood as External or Unrelated to Treatment Decision Making

In this study, participants (patients, family members and HCP) were not routinely familiar with the specific terminology of "advance care planning" and did not seem to experience ACP the way it is described in the literature, as a process of determining patient goals and values to inform health decision making (Rietjens et al., 2017). Peter (Patient, Case 3), Andrea (HCP, Case 4) and Judy (HCP, Case 6) were unfamiliar with the language of "advance care planning" when asked about it in an interview. Participants understood ACP as "general conversations" (Judy, HCP) that were shaped by legal frameworks and terminology related to resuscitation, wills and power of attorneys. However, the details of what these conversations entailed was limited:

Tieghan: Can you explain advance care planning for me, or what you see are the important elements of it?

Judy: Oh I should, uh... yeah. {Long pause}. I think it's just have the general conversation, and this includes me too, that everybody should have a will, and power of attorney and kind of express what your wishes would be. Just sort of starting to have that conversation earlier on.

(HCP, Case 6)

There was a sentiment from both patients and HCP that ACP, or these kinds of conversations should be happening routinely and are something that "everyone should have" (Judy, HCP, Case 6). However, the components of the process were not clearly identified.

Tieghan: And have you heard about what we are calling advance care planning?

Peter: Hmm, I guess I don't know really know what you are referring to?

(Patient, Case 3)

Tieghan: So are there policies when you admit someone, do you have any requirements around advance care plans or does that evolve?

Andrea: {Long Pause} Advance care planning....with umm...?

(HCP, Case 4)

Patients, family members, and even HCP may not approach ACP because the understanding of the process and the outcomes are so vague. Nathan described how ACP was the equivalent of palliative care; deeply connected to the social experience of dying, yet there were few concrete details that participants associated with the process of ACP.

## 26.1 ACP as a Legal Process: ACP as an Idealized Application of Informed Consent

Current models for ACP are built upon the practice of obtaining informed consent and therefore follow a process of providing information to patients, with which they and their SDM may discuss potential future situation in order to allow SDM to provide informed consent on the patients' behalf in the future:

“In Ontario, the law requires all health care providers to get informed consent, or refusal of consent, before providing a patient with any treatment or care. Health practitioners must tell you about your illness and what may be done to treat you. You then have the right to make a decision and agree to or refuse the treatments offered. This is called health care consent: it is a basic patient right to decide what health care to receive.

Only in emergencies, to save a life or to reduce suffering, can people be treated without informed consent. Consent always comes from a person: either the mentally capable person or their substitute decision maker(s). If you are not mentally capable, the health practitioner will turn to another person, your substitute decision maker, who will then speak for you and make the decision about your care. Advance care planning lets you know who would speak for you.”

(Excerpt from Speak Up Ontario Booklet)

Being informed is a necessary component of individual autonomy and is therefore a key aspect of ACP. In the Speak Up Canada Framework for ACP, “Learn” is the second component of ACP which involves “learning about different medical procedures and what they can or can’t do” (Speak Up, Case 5). As highlighted in earlier chapters, ACP is based on the process of informed consent, and the two requirements of informed consent are agency



(or voluntariness) and information (Stoljar, 2011). Both Hospital Centre A and Hospital Centre B have policies on informed consent that cite four specific requirements:

For consent to be valid:

1. it must relate to the treatment
2. it must be informed
3. it must be given voluntarily; and,
4. it must not have been obtained through misrepresentation or fraud.

(Consent to Treatment Policy Document, Hospital Centre B)

These four requirements can be reduced to the provision of accurate information and the existence of voluntary agency by the person providing consent. Additionally, Hospital Centre B outlined that to have informed consent, the health practitioner must:

- Give the patient information that a reasonable person in the same circumstance would require in order to make a decision.
- Provide the patient with information on the following matters and respond to the patient's requests for other information about these matters:
  1. the nature of the treatment(s)
  2. the expected benefits
  3. the material risks
  4. material side effects of the treatment
  5. special or unusual risks
  6. the alternative courses of action, and
  7. the likely consequences of not having the treatment

(Consent to Treatment Policy Document, Hospital Centre A)

These requirements are met when consent for surgery or medical procedure forms are signed, indicating that a patient had exercised their individual autonomy by actively making an “informed decision” or “informed choice”. HCP participants in this study acknowledged that being informed included providing good information on the life limiting nature of the HF and was a necessary requirement for patient autonomy. However, the type of information that was considered “good” was seldom identified:

“Hmm, like any other healthcare decision I think what’s important is that people have good information and have time to reflect, have the capacity to make a reasoned decision, which with some people can kind of wax and wane.”

Christopher (HCP, Case 5)

In his interview, Christopher (HCP, Case 5) minimized the import of ACP by comparing it to “any other healthcare decision” and applies the principles of informed consent, which includes patients being fully informed and competent to make a voluntary decision. In reality, healthcare decisions are rarely made in a way that aligns so closely to theory, as Greg (HCP, Case 4) described that patients and their families rarely “grasp everything that was said” which limits their ability to be truly informed.

“So, often patients will come to me after they see their specialist and they might have decisions to make....they will bring in one or two kids, or a close friend and discuss what the oncologist said about choices or the neurologist said about dementia. There’s always a specialist involved. So, it’s usually discussing what the specialist is saying or has written to me or called me and told me. Rarely that a patient really grasps everything that was said.”

Greg (HCP, Case 4)

HCP participants highlighted the tensions between the requirement of an autonomous person to be “informed” and the reality of how challenging it is to truly inform people of their disease process in a meaningful way. HCPs act as the gatekeepers of important health information and may actually reduce opportunities to develop capacities that are necessary to exercise personal autonomy (Meyer, 1989; Dodds, 2000). As Greg noted, patients and their families rarely “grasp everything that was said” which limits their ability to be truly informed. Additionally, despite Christopher’s optimistic picture of the decision making process, there is not always freedom to exercise careful consideration and reflection within the time-constrained structure of the healthcare system (Meyers, 1989; Sherwin & Winsby, 2011) and capacity often is not questioned unless there is a cognitive diagnosis or an obvious reason to examine capacity (i.e. the person is disagreeing with the care plan or is at the EOL). Therefore, ACP is based on an idealized application of informed consent.

## 26.2 ACP as a Personal Process: Wills, Personal Finances and Burial Arrangements

Participants' understanding of ACP was also related to the social conditions under which families manage and plan for death (Sherwin & Winsby, 2011) and the legalities associated with death such as wills, as mentioned by Judy (HCP, Case 6). Both provider and patient participants described how they associated ACP with personal family experiences where there was a strong focus on finances and funeral arrangements, as these were understood to be aspects of life that participants or their family members had clear control over. When asked about ACP, Nathan (HF Patient, Case 1) mentioned that he and his wife Tracey had previously had ACP discussions due to his many surgeries and complications, however, when prompted about the details of these conversations, he revealed that the focus was mainly on funeral arrangements for after his death:

“Hmm, there wasn't too much that was important to me other than maybe some funeral arrangements and stuff like that.”

Nathan (Patient, Case 1)

As opposed to framing ACP as the connection between personal values and treatment choices or “expressing wishes” or care preferences prior to death, participants were primarily concerned with arranging for funeral and burial plans and ensuring finances were in order once the person had died, as these were aspects of life that clearly fall within family responsibilities.

Similarly, when asked about her experience with ACP, Judy (HCP, Case 6) immediately relayed her personal experience supporting her mother and aunt through the financial planning and funeral planning process:

Tieghan: How did you learn about advance care planning?

Judy: My mother is going to be 99 in January - my sister's been my executor and power of attorney for my aunt who passed away and my dad who passed away and she is looking after our mother's financial affairs. She has got everything on spreadsheets and transfers money here and there. Yeah, so it's just the whole process I think, my parents have always been sort of proactive in sort of that regard. They, they bought, they bought pre-planned funerals, not the funerals but they have made arrangements to for cremation and, and plots and stuff and when they were in their 60s.

Tieghan: Do you have any experience having these kinds of conversations with patients and families that you work with?

Judy: Hmm, nothing recently comes to mind.

(Case 6)

Betty (HCP, Case 1 & 5) also answered the question by describing a situation with a family member being hospitalized. She participated in discussions about the appropriateness of resuscitation with the family and described how “challenging” this was for them, despite the fact they had personal connections to healthcare providers and ethics support. Throughout the study, many HCPs who were interviewed used personal examples to describe EOL decision making as opposed to providing clear examples of their professional role in ACP or experiences integrating patient goals and values into their treatment decision making. Taken together, this understanding reflects how ACP is seen as external to treatment decision making. For participants in this study, ACP existed within social relationships and was grounded in personal, as opposed to professional, responsibilities (McLeod & Sherwin, 2000). Participants connected ACP to aspects of life outside of the healthcare system and even outside of medical control (i.e. pre-paying funeral expenses) that may have influenced their ability to approach and participate in ACP within the context of professional or clinical relationships. This understanding also highlights the role that social and economic conditions play in the experience of ACP, as it occurs within the social landscapes of people’s lives and cannot be removed from the context of relationships and power dynamics (Sherwin & Winsby, 2011), especially in regards to both the legal and financial frameworks that guide social behaviour after death.

## 27 Approaching ACP as Documentation: The Collision of Legal and Biomedical Models

When participants approached ACP, they described the legalities of consent and substitute decision making colliding with the biomedical model of curative interventions and technology, which combined to produce an understanding of ACP that was primarily grounded in resuscitation status.

## 27.1 Consent and Resuscitation Documentation

When participants did feel that they understood ACP, it was often characterized as the process of obtaining resuscitation status (“code status”) or signing a “Do Not Resuscitate” (DNR) form.

When I asked Peter (HF Patient, Case 3) whether he had discussions with his wife about ACP, he admitted that he had not had many conversations about this, but that his family physician had mentioned that he “should be establishing resuscitation or non-resuscitation”. Peter also mentioned that he had been having discussions with Rose, his nurse practitioner, regarding his resuscitation status. “Code status” was required documentation for admitted inpatients based on hospital policy. At the time of the interview, Peter had not decided whether he would like resuscitation or not because he was concerned that he “didn’t understand it well enough” to be able to make a decision.

Peter’s experience begins to demonstrate the way dominant discourses related to medical treatment and the legalities of resuscitation and consent are combined with historical context to heavily shape the practice of ACP (Sherwin, 1998; Sherwin, 1992). In this example, ACP was quickly reduced to the process of obtaining resuscitation status, which can be quite disconnected from the broader context of illness decision making. Similarly, Marie (HCP, Case 5) highlighted that in her cardiac ICU setting, the important decision that needs to be made by people with advanced HF is “code status”. She often received patients who were quite sick, intubated and unable to speak for themselves, so from a practical clinical perspective, there was a need to obtain the resuscitation status because the patient was likely to deteriorate, and this documentation was meant to dictate clinical care. This exemplifies the tension that exists between the definition of ACP as a broad process of uncovering values, goals and beliefs to be incorporated into treatment decision making, and the stark reality of HCP who are faced with limited time, along with critical and emergent situations, and are required to make sound medical decisions that also follow the law.

Multiple participants, including patients Nathan (HF Patient, Case 1), Marty and Marty’s wife Brenda (Case 3), equated ACP with “do not resuscitate” documentation. They were both familiar with the term “DNR” and brought it up without being prompted. As opposed to being unfamiliar

with the language of ACP, these participants felt quite confident that what I was referring to as ACP was really DNR:

Tieghan: And when you did that [POA documentation with the lawyer] often they will do a living will or an advance directive document alongside it. I don't know if that was something that you had?

Nathan: Like a DNR or...?

Tieghan: Along those lines, or any specifications around what kind of care or treatment you might want?

Nathan: Not specifically no.

Tieghan: Not specifically okay. And the DNR, is that something you are familiar with or you had?

Nathan: Yeah, do not resuscitate.

(Patient, Case 1)

Marty: My doctor knows that it's DNA [DNR] [referring to existing ACP documentation]

Tieghan: Oh okay, what does that mean?

Brenda: Do not resuscitate.

Marty: Do not resuscitate.

Tieghan: Okay and when did that decision take place?

Marty: Many years ago.

(Patient, Case 6)

This familiarity with the concept of “DNR” again illustrates the reduction of ACP to decisions regarding resuscitation. The decisions that patients see as under their control relate specifically to resuscitation (specifically refusing resuscitation) but seem to exclude decisions about the treatment plan leading up to the resuscitation point or any involvement in conversations regarding consent. There also seems to be a limited relationship between the DNR documentation and the actual treatment plan, as both Nathan and Marty had recently received extensive and invasive procedures (heart transplant, CRT-P insertion) without connecting these treatment decisions to the existence of a DNR document. The legalities of consent combined

with the overarching understanding that biomedical treatments should be pursued until the time of death together created a very limited role for patients looking to participate in ACP, and the only method available to help them approach the ACP process and enact their autonomy was DNR documentation. This example illustrates the way that social context significantly influences the opportunities one has to develop and express autonomy skills (McLeod & Sherwin, 2000). Despite ACP being conceptualized in the literature as supporting treatment decision making throughout the illness trajectory and into the EOL phase, participants understood ACP as way to support the autonomy of people only at the point at which they require resuscitation, and the system is constructed to only allow them true participation via legal documentation at this point. Beyond this, HCP and institutions control the legal documentation and therefore participants identified resuscitation as the only medical decision point (while the patient is alive) where patient and family input was required.

## 27.2 Reducing ACP to Documenting “Previously Expressed Wishes”

Data collected from ACP policy documents were built entirely around the concept of “previously expressed wishes” (ACP Policy, Hospital Centre A). This was reflected by HCP who frequently highlighted that ascertaining “what patients want” was a key part of ACP:

“And for me, advance care planning would be a discussion of what the patient would want in the event that something terrible happens to them and they are not in the mindset or able to have a conversation about what they want, but to have it pre-emptively and ahead of time so, that we respect their wishes.”

Marie (HCP, Case 5)

In this transactional model, patients must outline what they “want” so that HCP and SDM can easily follow these requests, seemingly with the goal of eliminating distress and the potential for bad decisions, or decisions that don’t align with patient preferences, to be made. Both institutional policies and healthcare providers in this study seemed to view patients as having stable core values or preferences that could be easily documented and communicated to their SDMs or healthcare teams. Each agent’s particular social location is influential in establishing priorities, concerns, values and beliefs (Sherwin & Winsby, 2011), and people learn behaviours through relationships and responsibilities within communities (Sherwin, 1992; Sherwin, 1998).

Because of the social context shaped by biomedicalized policies and practices, ACP was understood by HCP as a process of discovering and documenting these desires and wishes in order to produce straight-forward and rational decision making process in the future, as demonstrated by Betty and Christopher:

“I encourage them to read it [Speak Up ACP booklet] on their own and then have the people who are important to them read it over and, and then for them to have a family discussion around the items that are listed in the booklet, and especially to have a meeting one to one with the person that they are going to have as their power of attorney so that that person has a really clear idea of what they want. And I’ll review, you know, it could be a medical intervention that you can’t speak for yourself, but they might want to try new medication on you or a new surgical intervention or whatever. So, the person making a decision for you has to have an understanding - would you want that?”

Betty (HCP, Case 1)

“So in the case of implantable devices of any kind I think that sometimes these devices have the potential to outlive the patient or at least continue working after the patient’s quality of life becomes such that they don’t view life prolongation at any cost as the goal. And as a result I think it’s important to have conversations at the outset about whether there were circumstances where they would want a device turned off or they would want to discontinue dialysis, there might be a little bit less important to document this until they get into that situation.”

Christopher (HCP, Case 5)

By combining the legalities of consent with the biomedicalized model of treatment decision making (Morgan, 1998), Betty, Christopher and Marie (HCP, Cases 5) all constructed ACP as a process that equates patients’ desires or “wants” with choosing specific interventions in advance (such as “new medication”, “new surgical intervention”, device deactivation or discontinuation of dialysis, etc.) and dictating these decisions to the SDM. Furthermore, this focus on resuscitation and understanding the patient’s previously expressed wishes, often reduced what would be a complex process of understanding patient “wishes” to the simplified process of documenting resuscitation status, as outlined by Andrea:

“Yes, I ask them during the initial assessment we ask them about what their wishes are so they sign either a CPR or no CPR, so that was what we put in place so on their full assessment and care plan - we put the code status.”

Andrea (HCP, Case 4)

In comparison, patients’ goals and priorities were aligned with their social location and their intersecting relationships and responsibilities (McLeod & Sherwin, 2000). Patients desired more



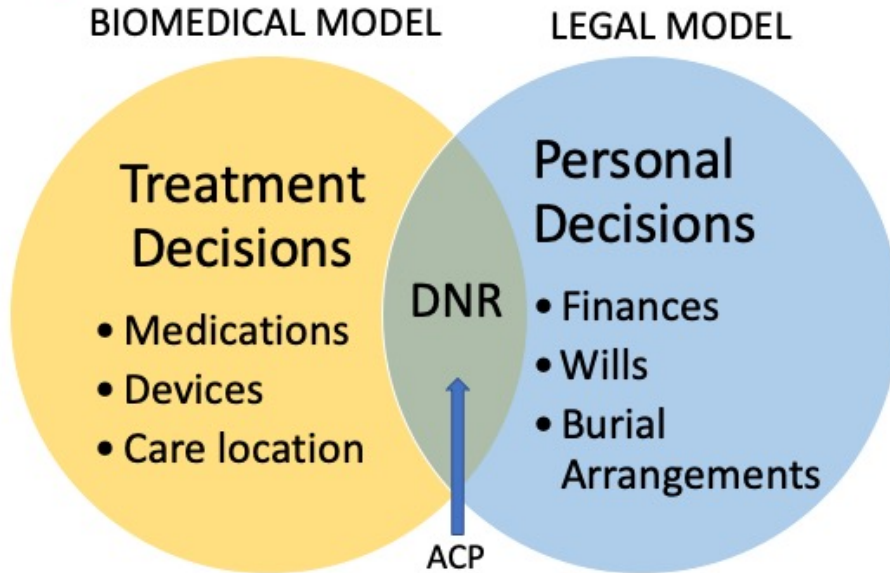
time with their families, desired not be a burden and many stated they were “ready” to die and had “lived a good life” (Alvita, Case 2; Diane, Case 4 & Marty, Case 6). However, these desires were rarely framed in the biomedical language that HCP were seeking in the context of ACP (i.e. “wanting” or not wanting a specific surgical or medical procedure). This begins to demonstrate the incongruence between the biomedical and legal decision making models, and the reality of the experiences of HF patients who are social agents located within a web of interconnected relationships and responsibilities, and whose wishes and desires are defined in relation to the important people in their lives (McLeod & Sherwin, 2000; Sherwin, 1998).

## 28 Conclusion to First Results Chapter

In this chapter, I answered the first research question of this study: “how do people living with heart failure understand advance care planning?” by providing a description of the field of ACP in advanced HF. In addition, I described the current biomedical and heart failure treatment field to provide context for a discussion of the various understandings of ACP. I then moved on to discuss the multiple models (i.e. biomedical, legal, personal, social) that shape the phenomenon of ACP, and concluded that participants primarily approached ACP through the process of determining resuscitation status, although resuscitation status often did not influence or affect their treatment decisions. This highlighted a key finding in this study, which is that ACP is understood as external to treatment decision making. In the following results chapters, I will build on this discussion of the various understandings and models that guide ACP by examining the experience of autonomy within the context of advanced HF.

Figure 2: ACP is External to Treatment Decision Making

**Key finding #1: ACP is External to Treatment Decision Making**



**Figure 2:** Although ACP is outlined in theory and in research as an attempt to overlap the biomedical and legal models of decision making and incorporate personal preferences, values and goals into treatment decision making, in clinical practice, ACP was often reduced to decisions regarding resuscitation.

## Chapter 7

### Results 2: Agency is Constrained in Advanced HF

One of the goals of this research was to examine the ways that people living with heart failure experience and express their autonomy through the process of ACP. In order to do this, it is first necessary to outline how people's experiences with autonomy may or may not align with the concept of individual autonomy that is employed in dominant approaches to biomedical ethics and healthcare, where autonomy is enacted through the practice of informed consent. This chapter will present the ways that the requirements for informed consent are threatened by advanced HF. Specifically, this will be done by illustrating how the complexity of the disease and treatments limits understanding, how patients perceive "no choice" which limits voluntariness, and how protocols and guidelines constrained the ability of participants to exercise agency over treatment decisions. The following chapter will examine the way participants experienced autonomy within the context of HF-ACP, and how the dominant model of individual autonomy did not align with the reality experienced by people living with advanced chronic disease.

### 29 The Idealization of Being "Informed": The Limits of Information

Information is a necessary component of individual autonomy. However, patients consistently described HF information as complex and difficult to understand, and clinicians frequently described the immense challenge of ensuring patients were adequately informed. Throughout this study, HCP participants highlighted the tensions between the theoretical requirement of ACP, that an autonomous person be fully "informed", and the reality of how challenging it is to truly inform people of their disease process in a meaningful way. This focus on information provision presupposes that ethical concern should be directed to the information giving and non-interfering actions of the clinician, instead of focusing on supporting the decision making process of the patient (Stoljar, 2011; Sherwin & Winsby, 2011). For example, Rose (HCP, Case 3) noted that "ideally once a patient is diagnosed with the heart failure, the information should be given that heart failure is a chronic disease". She also noted that "ideally" this should be discussed at the

time of the first diagnosis of disease. Despite Rose's (and other professionals') understanding the need for information to support patient autonomy, she went on to outline how it is "not rare" that she encounters patients who have very limited understanding of the nature of their disease.

Focussing on information provision also ignores the ways in which health care practices influence the development or demise of personal capacities for autonomy, which has been critiqued in relational approaches to autonomy (Meyer, 1989; Stoljar, 2011; Sherwin & Winsby, 2011). Despite the view that a key component of consent and ACP was that patients should understand their disease process and the potential outcomes of various treatments, participants highlighted the difficulties associated with trying to inform patients about the nature of their illness. The following section will examine the ability of patients to be truly informed within the current biomedical system.

## 29.1 The Impossibility of Being Informed within the Biomedical Sphere

Heart failure is complex and complicated, and people's understanding of ACP was linked to their understanding of HF. Daniel (HCP, Case 3) highlighted the extreme complexity of HF, especially in regard to prognostication, and the limited ability of HCP to translate such complex information to patients. Daniel saw this information primarily through the lens of the biomedical model, as decision making was based on prognostic curves and mortality rates, however he was also frustrated with this approach as it was not accessible to patients and families. He seemed to be stuck between these biomedical models, which provide generalized aggregate data, and the complexities of treatment decision making at the individual patient level:

"Explaining the standard deviation of prognosis in heart failure and that we say 50% are dead in 5 years, and you will see that stat sort of quoted, and that's worse than a lot of cancers. But of course 50% in 5 years doesn't mean – like when you say 50%, it doesn't mean that everyone is concentrated around that 50%, like some live 4 or some live 6 years. So it makes you sound like you are giving them a 5 year life expectancy and people don't understand the mathematics of what the prognosis curve of heart failure is and you have to show them these things and these curves. And so your heart is not failing, yes, it's 50% in 5 years but that includes like a lot of 90 year olds who have heart failure who are not going to live 5 years, they're not gonna live one year.

Heart failure is this thing that even I have trouble teaching internal medicine residents like – what is heart failure? It’s a syndrome, it’s a description of syndromes that partially relates to heart, partially relates to kidney and, and the prognosis is highly variable and even in experts we’re not that precise is being able to accurately estimate prognosis. So, it does make it a challenge in heart failure itself but then you throw on the fact that different people have different understandings and mortality and even if they knew what the prognosis was like well, how they integrate that, how they understand risk, and I mean all of this is quite variable between people.”

Daniel (HCP, Case 3)

In this collision between broader biomedical ideals and the personal patient experience, patients were expected to take in complex biomedical information and integrate this with their own understanding of “risk” and “mortality” in order to provide informed consent and participate in any meaningful decision making for current or future care. This would be a challenging task for anyone, let alone for someone living with an advanced chronic disease who may be suffering from cognitive impairment, pain, or other issues. Patients and caregivers trust HCP to provide health information and guide decision making, however complexity increases when patients and their family members are managing multiple components of self-care such as diet and fluid restrictions, medication regimens, etc. Complexity is also extended to the number of relationships patients engage in to manage their disease. Tracey, acknowledged the numerous healthcare providers involved in caring for chronically ill patients:

“I think it’s having an informed idea of what your disease processes are. And deciding, when you do receive a diagnosis, I guess as you digest that I think it’s important. I don’t know if I would start it at the family doc level or where it is right to start.”

(Tracey, Case 1)

As a family member Tracey understood the need for patients to receive information about their disease in order to make decisions, with an acknowledgement that there are a variety of HCP involved in the process of caring for chronically ill patients and that this type of information-provision process could start at any point of care. The complex nature of the HF, the biomedical treatment, and the challenges translating this information to patients and families may limit how patients and caregivers “understand” HF. Han (Patient, Case 5) and Katharine (Pam’s daughter, Case 7) felt they had a decent understanding of what was going on with their illness (or their family member’s illness), and saw themselves as prudent, responsible, and rational decision

makers. However, both expressed that they really “don’t know” whether they were dying, or if their family member was in “grave danger” or not:

“To be honest one of the big issues I am struggling with right now, yes, I am taking medication, but I can run around, go everywhere. Yes, my heart is weak, but at least I am not dying yet. Or maybe I am dying. I don’t know.”

Han (Case 5)

“This is the first appointment that I am coming to, I don’t know if maybe I just don’t understand the gravity of what’s going on, but I mean as far as I know she has heart failure controlled by medication and is not in grave danger as of today. But again that’s just my opinion as what I’m relayed from her and my sister. This is the first time I am going to be meeting the doctor, actually hearing what she has to say so I may have a different opinion of what’s going on after that appointment.”

Katharine (Case 7)

Although they stated they did not “think they are dying” or were in “grave danger” Han and Katharine both recognized that they did not completely understand the disease in all its complexity. This led them to believe that perhaps they could be dying or seriously ill and not be aware of this information because HF is so challenging to understand. For some, a particular area or system of the body can be highly medicalized (i.e. cardiovascular system) while the remainder may not be experienced through an internalized “medical gaze” (Morgan, 1998). This type of duality was experienced by Han (HF Patient, Case 5) who noted that he knew his heart was “weak”, but he was still able to “go around” and do the types of activities he wanted to do. Because of this, some aspects of his life had become highly medicalized while others had not. This duality may cause it to be challenging for patients to explain to their family members exactly what is going on with their illness. Judy highlighted this issue:

“Often times patients are coming in on their own when they are fairly well and they are managing on their own and it’s when the family members show up that you realize a) the patient needs more help and b) sometimes the family members had no idea how sick they were and what like what, what kind of trajectory they were looking at. So, it’s then trying to educate them about no, he is pretty sick, and just get them up to speed with that the whole trajectory and what the illness is about. Yeah, especially a lot of men that are maybe sort of on their own or are very independent and then as they start going downhill and then family members show up and they are just....the patient themselves probably haven’t sort of been straightforward with the family members, so.”

Judy, (HCP, Case 6):

Judy's example was almost exactly the experience of Peter and his nurse practitioner, Rose. Peter was quite independent and although he had lived for a long time with HF, he was now reaching the end stages of the disease. Rose (HCP, Case 3) described how despite his advanced age and obvious frailty, Peter's son was shocked when he was told how ill his father was:

“And even with their condition it's not necessary they are aware okay, you are at the end-stage right? And yeah, even the other day we talked to his [Peter's] son, it's like brand new information. He didn't know that – “oh my God, my dad is in such a poor condition.””

Rose (HCP, Case 3)

Peter's story provided another example of the impossibility of being “informed” and how it impacted ACP specifically. ACP requires not only the patient themselves be informed, but that their SDM be aware of the illness trajectory, engaged in the process and able to confidently make decisions on behalf of their loved one. Rose and Judy both demonstrated how our emphasis on individualism and independence often has the unintended consequence of family members not being included in education and decision making earlier on in the disease trajectory. This resulted in family members who were left with a very limited understanding of the health status of their loved one. Without sufficient understanding of the disease, de-contextualized “wishes” may be meaningless. The individualized focus of ACP policies and interventions mirrors biomedicine's tendency to approach illness as primarily a problem of individuals, rather than providing a contextualized understanding or acknowledging the social arrangements that may contribute to the problem, such as the fact that biomedical treatment is often presented as the only solution to patients' problems (Sherwin, 1998).

### 30 Autonomy is Constrained by Protocols and Guidelines

The biomedical model is grounded in discourses of science and the primacy of evidence-based practice (Morgan, 1998). Evidence-based practice may constrain agency through the use of evidence-based clinical guidelines and protocols, which prescribe optimum treatment and dictate clinical pathways. Adherence to these guidelines limits the options patients can choose from. We

found that participants did not associate personal agency with treatment decision making because these decisions were primarily shaped and determined by guidelines.

### 30.1 Protocols Override Autonomy: Agency is Constrained by Candidacy Criteria

In this study, HF treatment decisions were shaped by strict candidacy criteria. These criteria dictated whether patients were candidates for the vast array of technological interventions available, from implantable devices to cardiac surgery, and from non-invasive valve replacements to heart transplant or mechanical circulatory support. This approach tended to locate agency and responsibility for decision making outside of the individual patient or clinician, and instead constructed decisions as clinical care algorithms that determined the treatment options that could be offered to patients. Here, Peter (Patient, Case 3) expressed that it had been “decided” that he was a candidate for a valve procedure in a process external to him, and Rose, one of his HCP, later confirmed that he had been “accepted” for the MitraClip® procedure:

Peter: They have the stress test to determine that I am more likely a good candidate for a valve replacement, but they can’t do it yet. They have to wait and get the fluid off of my legs before I can do that.

Tieghan: So, they are trying to figure out whether you are a candidate?

Peter: Well, I think that’s been decided.

Tieghan: Oh! Okay.

Peter: No, well, I think....well, decided as much as it could be without opening me up, because the stress test would give them that information.

(Patient, Case 3)

When Rose (HCP, Case 3) described how Peter had been “accepted” for this procedure, this decision was not attributed to any specific provider or person who had decided to accept his case and go forward. Instead, this was framed as a decision dictated by neutral candidacy criteria who deemed him “acceptable” to receive the therapy. Candidacy guidelines dictated care plans in such a way that decisions and treatment regimens were not seen to be made by autonomous agents (such as patients or HCP), but rather by the larger power of a “neutral” candidacy criteria.



The transactional process of making this decision did not seem to include an evaluation of Peter's goals, values, or preferences, and, therefore, there were limited opportunities for him to develop autonomy competencies related to this decision. If decisions throughout the illness trajectory are solely based on candidacy criteria and guidelines because these are viewed as the only legitimate way to address the illness, it becomes clear why patients do not quite understand the role of ACP in future care decision making (Morgan, 1998). This is also echoed in Sarah's (Daughter, Case 1) binary understanding of palliative care as something that would only be offered if her father was determined not to be a candidate for a heart transplant:

Tieghan: Did you have meetings with people from palliative care before the transplant or at any point?

Nathan: No.

Sarah: That was going to, that was going to come into place if he wasn't a candidate.

(Patient & Daughter, Case 1)

Constructing treatment pathways based on candidacy as opposed to on patients' needs and preferences demonstrates how little influence patients have in the decision making process. Marty (Patient, Case 6) shared the sentiment that decisions regarding his care were not based on any preferences, values, or quality of life considerations, but were framed as consequences of him not being a candidate for surgery:

Brenda: There was one decision that I wasn't there, and Marty made the decision to do some test that they wanted to do. It was during your first stay there, remember that?

Marty: Yeah, I forget what that test was but there was seven people in the room with that machine. They were checking the heart.

Brenda: Oh, they were checking to see whether he'd be a candidate I think for the valve surgery.

Marty: Yeah. [...] I know that Dr. McMillan is keeping me alive on medication because I am not a candidate for surgery.

(HF Patient, Case 6)

Healthcare providers also defined themselves and their practices based on candidacy, as these guidelines dictated what they were able to do for their patients. This meant that the agency and responsibility that come with autonomy were deferred to these guidelines, and patients seemed to understand that the justification for medical decision making was often based on these candidacy criteria. This is a clear example of the role of medicalization in the decision making process, as medical authorities exercise the highest level of control over medical knowledge and treatments (Morgan, 1998), and even HCP would defer their own agency to consensus-based national guidelines. Patients and families viewed HCP as people who were translators of medical information and test results, but who were not necessarily responsible for treatment decisions, and by proxy, patients and families did not see themselves as responsible for participating in this type of treatment decision making. This lack of autonomy even extended to HCP, as Marie expressed confusion regarding her role when patients were not candidates for advanced therapies:

Tieghan: Can you say a bit more about the situations you mentioned that you see here that frustrate you?

Marie: Oh, when a patient is intubated and they have like, end-stage aortic stenosis, they don't have kidneys, they have cognitive impairments and dementia and they are in a nursing home, they can't eat and then the patient arrests on the floor, and they come down and they are a full code and then the families will be like "can you do everything" and I am kind of like.....and they are not a candidate for surgery or TAVI or anything and so you are just like how am I supposed to...like, I am not sure what I am saving?

(HCP, Case 5)

Finally, Daniel (HCP, Case 3) discussed how clinical care guidelines can dictate treatment and might not be beneficial when they are taken at face value without tailoring the guideline recommendations to the individual patient:

"Yeah, I mean I think some cardiologists probably just like look at the guidelines, and there is no age cut-off on any guidelines. Like okay, if you qualify for this then you should go on this. They are a bit more mechanistic about it, and it's faster probably. But there's a lot of people that have defibrillators and re-implantation of defibrillators that...you know."

(Daniel, Case 3)

Here, Daniel describes how HCP may offload the responsibility for making challenging healthcare decisions by using candidacy criteria to justify offering or not offering specific treatments, but at the same time HCP were the only ones who had access to the guidelines and the knowledge required to make these types of complex decisions. This is another example of the way HCP can be “gatekeepers” of information and opportunities (Meyers, 1989; Dodds, 2000) and clinical guidelines are a set of “gates” that patients must successfully pass through in order to obtain treatment.

In her interview, Betty (HCP, Case 1) characterized participation in ACP as being “forced” and explained how it was “not voluntary” because it was part of the protocol. This rang true for many “decisions” in the course of HF management that were protocolized and were therefore not presented to patients as optional decision points:

“Hmm, what helps to have them participate [in ACP]? Well, it’s forced participation in a way {Laughter}. Like it’s not a voluntary thing because it’s part of the protocol. I mean if a patient comes in and they have to have a biopsy, they have to have a biopsy. They come here and we have to have a discussion about power of attorney. We have to have it.”

(Betty, HCP Case 1)

Later in her interview, Betty mentioned how her ACP conversations are usually quite positive and that “nobody has ever been resistant” to her broaching this topic. This demonstrated the power dynamic at play, and that patients did not resist in an obvious way because, as she said, participation is “not voluntary.” The individualistic view of autonomy often fails to recognize that patient-provider relationships are often characterized by a deep imbalance of power, which shapes the social context of healthcare decision making (Sherwin, 1998). This is another obvious example of the way that traditional autonomy and informed consent do not fit with the true patient experience. One of the conditions for informed consent is voluntariness, yet Betty notes that for patients, many aspects of care are “not voluntary.” This brings forward a discrepancy between the ideal of individualized autonomy and the reality of constraints that limit the ability to enact this type of autonomy. In this study, autonomy was clearly constrained by various factors related to relationships, opportunities and social location and, therefore, aligns with a relational view of autonomy that recognizes the presence of constraining and enabling forces and

provides an explanation of how these factors may influence people's sense of self and their ability to express autonomy (Sherwin, 1998). In contrast, the traditional individualistic view generally disregards the role of social location in the expression of autonomy.

## 30.2 No Roadmap: The Danger of Existing Outside of the Standard of Care

As a cardiologist working with an older population, Daniel (HCP, Case 3) felt strongly about his role supporting clients to achieve the best quality of life possible, which often meant providing active HF management at home. He was truly caught in the limitations of the combined legal-biomedical model, as he was required to take on a significant amount of risk and liability to prioritize his patients' goals over the protocols, guidelines and standards that generally guide HF care (i.e. providing intravenous diuretics at home, which does not allow for "appropriate" monitoring of bloodwork and cardiac rhythms). In his experience, existing in this liminal space "outside the standard of care" produced significant discomfort as neither the legal frameworks nor the biomedical guidelines accounted for the work he was doing, despite it being beneficial and what he believed to be morally necessary work:

"I spend a lot of time speaking to patients about what is it that they would want, how do they foresee the coming days mainly to gage how much investigation I am going to recommend. I do a fair bit of aggressive stuff at home which I normally wouldn't do unless I understand the goals of care. So, for example intravenous Lasix, that's not a standard of care. It's not standard practice, but I will offer it to patients if they accept the fact that there's risk of sudden death from arrhythmias related to metabolic disturbances. So, they have to agree that they understand that we're sort of existing outside of the standard of care, that normally that patient would come into the hospital, but if they are willing to forgo that and understand that there's a risk of it, but they would rather stay at home and their goals are to be at home as long as possible and they are not particularly perturbed by a sudden cardiac death then we go ahead and do it. There's no one there to resuscitate them so I just say that to them: "listen - what I am doing now it what we normally do in hospital, but you have to understand that this isn't the hospital. You are at risk of things that we potentially can recover you from in hospital and that would be the standard of care, but if you are willing to go and do this with me..." I am not giving Propofol to put somebody to sleep like MJ, but I am just you know...[Laughter]. I have no ethical issue with it, and they are allowed to do what they want and if the doctor is willing to do it for them then that's fine. I am not euthanizing them or doing medical assisted dying, the purpose of course is not to kill them."

Daniel (HCP, Case 3)

Daniel's distress with his role in the biomedicalized system was demonstrated through his constant need to differentiate the care he provided from assisted dying, or from doctors who kill their patients with medications. These comparisons demonstrated the incredible stress Daniel felt as he tried to support patient goals of care in a system that is not designed for this type of individualized approach. Daniel exhibited the epitome of shared decision making and the skill of tailoring patient preferences to specific care decisions, while also reducing hospitalizations and overall health system costs. This should have been praised, but instead he felt as though he could be accused of murder at any point. This illustrated the incredible amount of confidence and expertise one must have to align treatments with patient goals, and clearly showed why this so rarely occurred in a system that prioritizes standards of care and evidence-based protocols over patient preferences.

Daniel: Yeah [referring to charting], a couple of sentences that I discussed it with them, I have had a few notes where I have specifically written I have used the IV Lasix and they understand. We discussed their goals of care which is to be at home primarily on quality of life rather than quantity of life and so I have a standard sort of thing. I mean it's not a 5-page palliative care psychiatry consult. It's two sentences to say listen, I am not crazy with what I am doing here. I am not trying to kill my patients, but they want to stay at home, and they're congested, so we're going to give them IV Lasix.

Tieghan: Is there that viewpoint that if you let people stay home, that you're negligent or something?

Daniel: No, they may-... you know, you're always concerned. I think it's just from pathway perspective. It's really important for me to understand so that I don't expose myself medically, legally that there's transparency about what exactly I am doing.

In this conversation, Daniel highlighted the ever-present risk of liability that could be a challenge to providing care that aligns with patient goals. Even when making clinically sound decisions with the intention of supporting patient goals, there was still a sense that clinical guidelines and standards took precedence over patient values, and therefore any decision that did not align with practice standards needed to be explicitly justified, despite that it was, indeed, what the patient "wanted." This was important because it demonstrated how challenging it can be to truly provide the patient with what they "want", when the system is designed to prioritize safety, standardization and risk-minimization. Patients and HCP existed in a liminal space outside of the standard of care dictated by EBP.

## 31 The Illusion of Autonomy: Patient and Family Experiences Do Not Resonate with Traditional Individual Autonomy

### 31.1 Patients Do Not Experience Individual Agency in Treatment Decision Making

Agency was also constrained in advanced HF because patients perceived no opportunities to contribute to treatment decisions: their role was merely to accept the treatments proposed by their clinicians, which were based on clinical guidelines. Participants in this study did not experience many possibilities to participate in decision making throughout their health trajectory. When participants discussed treatment decisions or the experience of being hospitalized, decision making was clearly controlled by the healthcare team. This was demonstrated by patients referring to what “they said” (Tracey, Nathan’s wife, Case 1), “they decided” (Pam, Patient, Case 7) or “they were doing” (Brenda, Marty’s wife, Case 6) - the things HCP said or did to communicate the plan of care. The word “consent” was lacking from the participants’ descriptions of their experiences; there was not even a reference to this term or the process that is associated with it from the perspective of the patients or their families. Even when explicitly asked about their contributions, decisions and involvement in decision making, patients and family members rarely used the terms “I did” or “I chose”; they often described a limited and passive role that involved accepting the treatment decisions made by the healthcare team. Pam described her more recent diagnosis and the countless appointments arranged by her team as dictated to her (“go here, have this done, have that done”) and felt powerless without a sense of what her future may hold:

“So I fell apart at that point and then they decided to look further, get a CT scan and everything because right away I thought “oh God, the cancer is back,” and I was relieved when they came back and they said no cancer, but you have heart failure. Due to chemo. {Long pause} {Crying} And then everything just started, one appointment after the other, go here, go there, have this done, have that done and...oh my God, what are they going to tell me now?”

Pam (Patient, Case 7)

Some patients did hold strong views or specific opinions regarding their preferences based on their personal values, but their experience was that these opinions were not taken into account in

healthcare decisions. As Han described, he was informed that he “had to” have an ICD implanted, despite the fact that he didn’t want the device:

“They went back to my lungs, my heart, my kidneys, and they thought it was all caused by my kidney. Until I asked to leave, then they came back to me and said “Han, it was not the problem of kidney, it was a problem of your heart and you have to put this [cardiac device] in.” I object. I didn’t want it. I told her in the past 40 years I never have any cuts on my body, other than fingers, and then I object. But my cardiologist called me at home and told me: “you have to, otherwise you will be dying anytime.””

Han (Patient, Case 5)

This practice of shutting patients down, or “rejecting their decisions” as Han later expressed, left patients with limited opportunities to develop autonomy competencies and express their authentic desires within the context of health decision making (Meyers, 1998). Without any prior experience or opportunities to develop autonomy skills in this context, it may have been impossible for patients and their families to confidently and authentically participate in ACP. Social and political relationships as well as power dynamics that exist within the biomedical setting may be constraining forces and may interfere with one’s ability to exercise autonomy by limiting opportunities to participate in decision making (Sherwin, 1998). Patients lived with the burden of being a patient and having their lives dominated by medications, treatments, appointments, and self-management, and few opportunities to enact agency.

Despite the sense of powerlessness expressed by Pam and Han, some participants seemed to appreciate this model where HCP controlled decision making, and did not express a desire to be more involved or have more responsibility in the decision making process:

Tieghan: I am wondering when he was in the hospital, what kind of things they were asking your support with, or how you were involved with the team?

Brenda: Well, they were just letting me know what was going on and what they were doing.

Marty: They were all fabulous.

(Case 6)

Marty and Brenda (Case 6) held this perception; they expressed their satisfaction with the team and appreciated how they let Brenda know what was going on with her husband and “what they were doing”. Marty and Brenda seemed to expect that the healthcare team would manage the situation and make decisions throughout the illness trajectory. In this setting, HCP are seen as in control medical treatment, and their behaviours reflect this, as they update patients and do not necessarily seek consent at each individual decision point.

Family meetings seemed to only be relevant when there was no longer a plan, the HCP team no longer knew what to do, and family members were only asked to make decisions when things were not going well. Rose (HCP, Case 3) confirmed this from the HCP perspective. When asked about her role discussing the plan of care with Peter, she outlined that a meeting with Peter’s family was not necessary because the healthcare team “still had a plan” to provide him with the MitraClip® procedure:

Tieghan: Can you tell me about the meeting with Peter and his son, was that a family meeting?

Rose: No, no, no, because we still have a plan right? Like we’re still doing something, but it’s...we kind-of know it’s more to help with the symptom control so that maybe we can diurese well right? So, we gave them an update with regards to this.

(Case 3)

Similarly, when he was diagnosed with HF, Nathan was a young father and marathon runner. When the healthcare team was asked if he would still be able to run, they were optimistic. Tracey recounted:

“They said “oh no, he will still be able to run. We will put the ICD in and we will put him on the Sotalol [anti-arrhythmic medication] and then you know, it may go off once in a while but you know, for the most part, it shouldn’t interfere too much in his life.” Which was baloney.”

Tracey (Wife of Nathan, Case 1)

This demonstrates that when the patient is progressing through the treatment plan as determined by the team, HCP construct their responsibility as providing “updates” to the family (Rose, HCP



Case 3). There is no mention of having consent conversations or discussing and incorporating patient preferences alongside these “updates”.

Although none of the participants in this study expressed being responsible for health or treatment decisions, they were responsible for making many life decisions that were unrelated to consenting to specific treatments. Peter (Patient, Case 3) described how he and his wife significantly modified their life by moving homes based on his deteriorating health (among other factors):

Tieghan: Have you had to make any decisions about your healthcare recently?

Peter: We moved...for various reasons: one, because we were down here so often for medical reasons...my wife doesn't drive and so we moved down here three years ago and sold the house up there, bought the house down here. And we're very fortunate we did at the time because that's when immediately I started to have the heart problems that summer, the summer that we moved when I was in here that special stent procedure.

(Patient, Case 3)

This illustrates how the decisions patients saw as within their control were related to the personal, social, financial, etc. aspects of life, compared to healthcare decisions which patients perceived as controlled by HCP or the healthcare team. The influence of medicalization and the dominance of the biomedical model is clear, as individuals learn behaviours through relationships and responsibilities within communities, and identities are configured through both interpersonal and political relationships (Sherwin, 1992; Sherwin, 1998). This also demonstrates how people exist within an intersecting web of relationships and responsibilities and each agent's particular social location is influential in establishing their priorities and concerns (Sherwin & Winsby, 2011).

## 31.2 Patients Do Not Have “Choices:” The Coercive Power of Death

Patients often viewed themselves as having a passive role in healthcare decision making and having few options presented to them for decision making. They understood that their options were to accept the treatment proposed by their clinicians, or to refuse; however the risks of refusing treatments were severe while also unacknowledged. Patients expressed that accepting treatments meant they could stay alive, and refusing treatment meant certain death. This was

demonstrated clearly by Nathan (Patient, Case 1) who described the decision to have a transplant as a “non-decision” because the alternative was a certain death:

Nathan: Deciding to have a transplant was a big decision for me, but it was actually a non-decision in the end because I didn’t really have a choice, so.

Tieghan: Can you tell me a little more about that?

Nathan: Well, um... [Long pause] yeah, I mean, there was a decision process in whether or not I was going to have the transplant at all, and that was after I had gone through the work up and I had to decide that myself, but then when you hear what the options are, the second option wasn’t very good.

Tieghan: Which was what?

Nathan: Was to...I don’t know how much time I would have had but maybe a year, maybe two and that was it.

(Patient, Case 1)

Peter (Patient, Case 3) also expressed that he didn’t have any choice in his treatment pathway; he was being worked up for a MitraClip® procedure with the goal of improving his HF symptoms. This was a high-risk procedure considering his frailty and advanced symptom burden, and to receive the procedure he had to be hospitalized for a month in advance to complete pre-operative testing and treatment to ensure he was in the best possible condition to proceed with the surgery. Peter described how deciding to have the valve procedure was not his choice, rather, it was the only option provided to him:

Tieghan: When you are thinking about this valve surgery and what this procedure will entail, is there anything that is important to you when you are making that decision?

Peter: Hmm... {Long pause} well it’s basically that or nothing right? It comes down to that - not being given any options.

(Patient, Case 3)

Similarly, Han (Patient, Case 5) described how he was informed that he “had to” have an ICD implanted, despite the fact that he didn’t want the device. He explained how he objected to this recommendation but was told by his cardiologist that if he didn’t accept the device he could “die at any moment”.

Agency is constrained when patients construct consent to treatment as their only choice, as is the case in the context of advanced HF. Choosing between various medical treatments was not something that participants saw as within their domain of control, and patients described how they were rarely invited to participate in treatment decision making in the present moment. They were not asked about their wishes or treatment preferences. In fact, they didn't have specific desires or "preferences for care" but instead they had preferences for how they would like to live the remainder of their lives. For Nathan, this meant living to see his daughter get married; for Peter this meant helping his wife to raise their new puppy and go on a train trip across Canada. These decisions were external to healthcare decision making and were focused on their social context and interpersonal responsibilities (Sherwin, 1998). Wishes and desires were grounded in their social identities and the responsibilities they held to their families as opposed to wishing for specific types of treatment (McLeod & Sherwin, 2000). Participants expressed that it did not feel like "it had gotten to that point" (Tracey, Wife of Nathan, Case 1) where they would be asked to make a decision; this "point" is only when the patient is dying, and they have no choice but to stop treatment. This illustrates the covert power of the healthcare team in making decisions, as participants understood their role in decision making to be limited to stopping or refusing treatment at the EOL, as opposed to actively consenting to treatment or contributing to the plan.

## 32 Trust, Self-Trust and the Limited Power of ACP

In Canada, the National Task Force on Advance Care Planning has implemented the "Speak Up" campaign, a public awareness campaign seeking to increase participation in ACP through education and resource provision. This provides resources for patients, families, and HCP and has produced an ACP workbook which outlines the main components of the ACP process. Speak Up's ACP workbook aims to help people "think about what's important" to them and "what you'd want people to know if you couldn't speak for yourself" (Advance Care Planning Canada, n.d.) and breaks down the ACP process into five components: (1) think, (2) learn, (3) decide, (4) talk and (5) record. This campaign is based on an individualistic view of autonomy, as it uses language such as "making your wishes known" and supports the idea that in challenging medical situations, there is a "right" decision that can be made, which supports the underlying assumption that the "right" decision is the decision the patient would have made independently. Speak Up

also suggests that patient-centered decision making is the standard of care and involves: “incorporating patient perspectives, priorities and goals throughout an illness trajectory from advance care planning through to treatment discussions and informed consent.”

ACP as the standard of care is predicated on the assumption that informed consent is taking place the way it has been outlined in theory as well as in institutional policies and guidelines. In practice, none of the patients in this study completed a Speak Up workbook or identified with participating in the process of informed consent. Participants in this study did not hold the same understanding of the process of informed consent that is cited in the Speak Up workbook. Patients reported that they did not have opportunities to provide their “perspectives, priorities or goals” within their healthcare interactions. Overall, patients experienced limited (or non-existent) individual autonomy (as it is defined within the traditional framework) within the context of health decision making, and consequently, were obligated to trust their providers to guide the decision making process. Nathan (Patient, Case 1) described the situation where he was sent for emergency surgery and expressed that he couldn’t question the process; he had to resign himself to trusting that the surgeons would “do their best.” Similarly, Marty and Brenda (Patient and Wife, Case 6) described how much faith they had in their cardiologist and healthcare team, which bolstered their trust in the recommendations that were made to them regarding receiving an ICD, while Han (Patient, Case 5) expressed that he was obligated to trust HCPs because “they are professionals” and he was not.

Although it is often taken for granted that the relationship between HCP and patients is one of trust, especially when HCP are clinical experts in the field of HF management, there is less acknowledgement of the ways power dynamics and the vulnerability of the trustee shapes these relationships. The fact that patients are obligated or required to trust their providers due to their vulnerable position has implications for their ability to trust themselves and have confidence in the value of their own preferences, goals and opinions regarding their care. This ability to value their own expertise and preferences, and believe in their capacity to not only make appropriate choices given personal values and desires, but to act on these decisions and trust the judgements that underlie these decisions, is termed “self-trust” by feminist philosophers (Govier, 1993; McLeod & Sherwin, 2000). Patients seemed to lack self-trust because the complexity of

information meant that they were unable to fully understand their disease and make appropriate judgements regarding their values, desires and preferences in relation to their illness management. Additionally, the power structures within the healthcare system and privileging of biomedical knowledge demanded that they trust their providers to guide decisions, as was demonstrated by Han's (Patient, Case 5) experience:

Han: I follow the rules okay, whatever I am doing, I will ask you folks because you folks are professionals, know better than me about myself.

Tieghan: Do you believe that?

Han: Well, put it this way.... not really. {Laughter} In some ways, yes. Okay, you folks have all those diagrams, the charts and those frames, x-ray film, then you might have a better idea than myself right? So, I still have to trust you.

Han's struggle between trusting himself and trusting his healthcare providers highlights the tension patients experience between the ideal of individual autonomy and the reality of navigating through a chronic illness in a biomedicalized healthcare system. In this situation, Han was unconvinced that providers knew better than him, however came to the conclusion that he was required to trust that they did based on their biomedical expertise. This is an example of the inverse relationship that develops between trust and self-trust in the context of autonomy and treatment decision making specifically (McLeod & Sherwin, 2000). This also demonstrates the way that constraints, such as lack of biomedical knowledge, unequal power relations, and lack of opportunities or experience making decisions can all interfere with the development of self-trust, and reduced self-trust reduces an agent's ability to act autonomously. As outlined in the results of this study, the power relations within the healthcare system, the complexity of biomedical information, and the inherent vulnerability of the chronically ill can contribute to reduced self-trust and constrain HF patients from fully participating in the ACP process.

Patient participants highlighted this tension between trusting providers and trusting themselves and described the bind that they find themselves in when considering ACP specifically – in order to be motivated to participate in ACP, they must trust HCP to either follow the documents (or act in their best wishes because they “know” the patient, as Diane noted), yet at the same time they had experienced situations in which their ACP documents did not inform the care that they

received or that they observed. Diane (Patient, Case 4) was very adamant that she did not want to be resuscitated under any circumstances and had taken the appropriate steps to ensure this would not happen, but ultimately had resigned herself to the fact that she would have to trust the care providers at her residential home and the paramedics who would be responsible for making this decision. She noted how she was aware that these HCP occasionally provided resuscitation even when this contradicted a patients' previously expressed wishes:

Diane: No, don't extend my life and I don't want to have that pump going, what do you call that?

Tieghan: CPR?

Diane: Oh, that, no. Have a heart attack and get me back no, no, no. That's why I have it written down by a doctor signed, years ago. I have written that I am not having the, what do you call that, the pumping? That you have, when you have a stroke or a heart attack, they try to bring you back?

Tieghan: Resuscitation?

Diane: I don't want that. No. No, let me go, it's time for me to go.

Tieghan: Did you have anyone who went through that?

Diane: No, but I see what's going on here. Doctor signed, I have it on my chart. Well it's definitely done, and I keep telling everybody - they know it here too. But I mean if the ambulance comes, they do it anyways. I see it.

Tieghan: Okay, so do you have instructions around not even call an ambulance, or how does that work?

Diane: Oh no, they have to look after what they think they should do, they know me here.

(Patient, Case 4)

Diane described situations in which she observed ACP documents being ignored, but despite this, she did not view it within her purview to request that ambulances not be called for her. She placed her trust in the HCP who she worked with and who "know her" and depended on them to look after what they thought was best. In the above quote, Diane highlighted how even if DNR documentation is signed and one does not wish to receive resuscitation, when patients deteriorate, the ambulances are called and the paramedics "do it anyway" which caused her to

lose trust in the process. Nathan's expressed his distrust in ACP documentation by sharing his experience with doctors who ignore DNR documentation and "would rather do than read":

Nathan: There's different levels of DNR though from what I understand, and different institutions have different types so I don't know. Usually a lot of the times medical personnel don't follow that sort of DNR.

Tieghan: Has that been your experience?

Nathan: Well, my wife's experience. I mean they will come in and do something before they even look at a DNR, but that's what doctors do - they would rather do than read. I've had many times that people won't read my chart in depth whether they are new residents or medical students or even fellows sometimes. And they make mistakes on charts all the time. She's upset because I had a pleural effusion instead of the saddle emboli on my chart, back in 2016, a pleural effusion - no he didn't! {Laughing}.

(Patient, Case 1)

Nathan described his wife's experience of having medical personnel ignore DNRs or fail to review the chart, and his own experience of having HCP make significant mistakes in his chart. Through their varied healthcare experiences, participants experienced clear limitations in the power of ACP documents, as well as skepticism regarding the ability of ACP documents to truly guide the behaviour of their HCP. These experiences expose the power of medicalization and the social imperative to prolong life at all costs (van Heijst, 2009). This also highlights the obvious limitations to ACP documentation that patients observe through their experiences in the healthcare system. Overall, for participants in this study, ACP was understood as narrowly focused on EOL legalities and was therefore approached through a framework uniquely focused on documentation of resuscitation status, as opposed to a process that addressed the complexities of people's lives and interconnected relationships. Due to the dominance of the biomedical paradigm and the focus on life preservation (van Heijst, 2009), and combined with their lived experiences, participants did not fully trust that completing resuscitation documentation would guide the care they received, which may contribute to limited engagement in the ACP process.

### 33 Conclusion to Second Results Chapter

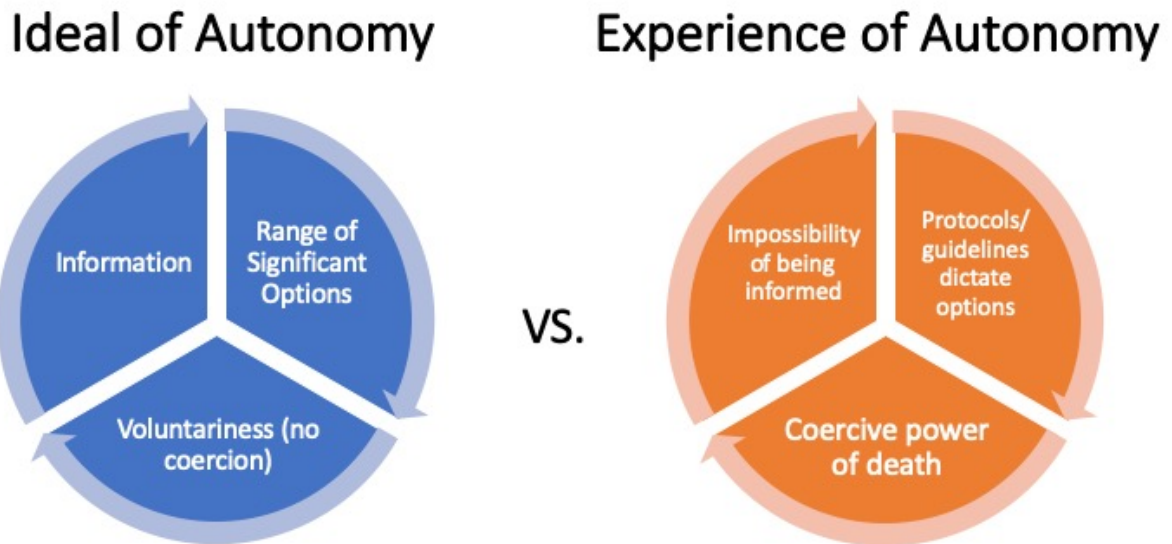
In this chapter, I answered the second research question of this study: "how do people living with heart failure express autonomy when participating in advance care planning?" by exposing the

incongruence between the traditional model individual autonomy (the dominant construct that underpins ACP in this setting) and the experiences shared by participants. This incongruity was demonstrated by outlining the ways that agency is constrained in advanced HF. Specifically, the lack of choices patients and family members have in the HF trajectory, the impossibility of being informed within the biomedical model, and the way that our protocolized and criteria-focused system constrains agency and limits opportunities for autonomy. This highlighted a key finding in this study, which is that agency is constrained in advanced HF, and ACP does not align with the individualistic view of autonomy that it has traditionally been associated with. In the following results chapter, I will build on this discussion by examining the relational reality of autonomy within the context of advanced HF, and the way that interpersonal relationships, social location and broad social forces influence the experience of autonomy.



Figure 3: Agency is Constrained in Advanced HF

**Key Finding #2: Agency is Constrained in Advanced HF**



**Figure 3:** The "ideal of autonomy" is characterized by 3 requirements: the patient must have sufficient information to make a decision, a range of significant options to choose from, and must make their decision voluntarily without coercion. However, examining the experience of autonomy of the participants highlighted significant incongruence between their experiences and the traditional model, as participants discussed impossibility of being informed, the way that the protocolized and guideline-driven HF care system dictated their options, and the coercive power of death which favours decisions to extend survival time by accepting treatment.

## Chapter 8

### Results 3: The Reality of Relational Autonomy

In this study, participants experienced their autonomy within a relational context; their autonomy was shaped by relationships, social roles and responsibilities. This experience of autonomy was not accounted for within traditional ACP conceptualizations or interventions that tend to isolate autonomy from the broader social locations of people, and from the broader context of healthcare decision making. The results presented in the following chapter demonstrate the realities of how autonomy cannot be isolated from the broader social, political, economic and relational contexts of people's lives and demonstrates how autonomy is deeply connected to family roles and responsibilities, relationships with healthcare providers, social location and social identities, and is influenced by dominant social discourses such as ageism, individualism and self-management that stem from neoliberal ideology. This chapter moves from the individual level, which focuses on interpersonal relationships, and then expands to address the institutional and social level influences that shape the experience of autonomy.

#### 34 Autonomy is Experienced Relationally: Family Roles and Responsibilities

The majority of patients and their family members in this study had very close relationships of mutual respect and support. Family roles shaped the illness experience of the participants, as people held a variety of roles within their families that were closely connected to the way that decisions were made, the way that emotions were managed, and the way that treatments were sought.

##### 34.1 Family Roles Shape the Illness Experience

Family roles shaped the illness experience in a variety of ways. In Han (Patient, Case 5) and Lily's case, Han was seen as stubborn and rigid because he was opposed to most of the biomedical treatment that was offered to him. Han's stubbornness was seen as a challenge to his family, and, therefore, their role was to convince him to make the "right" decision: to proceed with transplantation. Han described how his wife and children all discussed his choices (both

with and without him) and worked together to encourage him to agree to proceed with the heart transplant:

Lily: I call him trouble-maker... {Laughter}

Han: That's my nickname between them [wife and kids].

Lily: And I told them [the kids] that he's considering doing the transplant right now.

Han: Yeah, she told the kids...

Lily: They want to celebrate this with him.

Tieghan: I see okay, so they are excited?

Lily: Yeah, see because no one can, can convince him doing anything, he won't do it.

Han: I am stubborn.

(Case 5)

This excerpt demonstrates how Lily leveraged the power of their children and Han's desire to please their family to steer him towards agreeing to the heart transplant procedure. Although this was completely normal for their family, this type of behaviour is not aligned with the traditional model of individual autonomy and is seen as a problem to mitigate, as Christopher (HCP, Case 5) outlined:

"Even with transplant recipients there is always the possibility that a patient's spouse might be pushing them to get a transplant because they have comorbidities. A lot of patients who are experiencing organ failure also have cognitive impairment and that may be a bit of a burden on their caregivers at the same time. We would want to make sure someone isn't steered into something that's not right for them, simply because of that effect on a third person however close they were."

Christopher (HCP, Case 5)

Despite the way Christopher outlined that individual autonomy should be applied theoretically, Han's family members worked together in conjunction with healthcare providers in order to steer him in the direction of agreeing to what they considered to be the "right" choice of pursuing a heart transplant, despite knowing he did not agree. This type of cooperation also occurred in Pam's (Patient, Case 7) family, as her daughter Katharine highlighted the role she and her siblings played in encouraging her mother to seek treatment and make decisions:

Katharine: And then one doctor told you “oh it’s a 100-day cough.” That’s why we said to her “Mom, if you are not comfortable with what they are telling you just go to the hospital and they will figure it out.” So, that’s exactly how we got here to be honest with you. Otherwise if we hadn’t sort of scared you into that...

Pam: If you hadn’t actually said that, if you hadn’t said it that week...

Katharine: You might not have gone.

(Patient, Case 7)

Pam’s ability to make the “right” choice and feel validated in seeking healthcare was attributed to her relationships with her children and their encouragement and support, however the significance of family relationships goes beyond decision support. Pam’s daughter Katharine outlined the important role that she and her mother have for each other in helping to manage emotions in general:

“Having said that though, when I am on this side of the coin and I am flying off the deep end, she is the one pulling me back down saying “you need to chill” {Laughter}. Yeah, so my mom and I have very similar personalities and although I am very realistic, I am very quick to run away with my thoughts and it’s the end of the world. So, she’s my reality and I am her reality, we just can’t do it for ourselves. That’s why I am more of the “okay, Mom take a step back listen to what the doctor is saying and don’t take it to the extreme if it is not there yet.” That’s my role. And that’s why I am able to say to her “stop, I know where you are going with this, stop.” And people look at me like I am a hard-ass and I am, but I need to be {Laughter}. Because I have been on that side of it where it’s so easy to think that it’s the end of the world. Like when you complain about how I have to take my pills, well who cares like at least you can take your pills and it’s controlled by the pills right?”

Katharine (Pam’s daughter, Case 7)

Here, Katharine clearly articulated her relationship with her mother by describing how “she’s my reality and I am her reality.” Her role was to help her mother manage the intense and scary nature of receiving and integrating important health information within chronic illness. This demonstrates the inextricability of interpersonal relationships, not only for decision making or emotional support, but for the construction of reality as whole. People cannot isolate themselves, or their values and goals from the interconnectedness of their daily lives (Sherwin 1989a) and having relationships with people inherently means that there are shared goals that exist between the two people. Therefore, it may be impossible to isolate what a patient truly “wants” from the

context of their relationships and the desires and goals of the people to whom they are connected to.

This was also illustrated by Han's description of the differences between accepting treatment recommendations when he was 50 and still had significant familial and financial responsibilities to motivate him, compared to at 65, where he has fewer familial and financial responsibilities. This seemed to shape the way he constructed the decision making about the potential transplant:

“Another thing I am considering is age. That time [ICD insertion time] I was 50 okay, now I am 64 going, turning to be 65 - this is another concern. When I was 50, I was more positive, I have to get it done. Why? My kids were still young, I still have to pay the bills, mortgage everything. Now, they are grown up, they have their own life. And financially we are okay, that's why - my role changed.”

Han (Patient, Case 5)

The importance of family roles clearly plays a part in the way people construct their decision making and their interest in pursuing treatment or participating in ACP, as Rose (HCP, Case 3) also highlighted that people are more likely to participate in making legal and financial arrangements “especially when they have young children.” This example illustrates that people's identities and decisions are the product of interpersonal relationships and highlights the importance of locating a person's unique positioning both within multiple social groups as well as within personal relationships (McLeod & Sherwin, 2000).

## 34.2 Morality Exists in Interpersonal Responsibilities

There is a significant burden of responsibility involved with caregiving and being a SDM, and the intense moral experience of holding this role is not often acknowledge in traditional conceptualizations of ACP. Both Betty (HCP, Case 1) and Greg (HCP, Case 2) outlined how much work it is for family members to manage the health of their loved one, and Betty highlighted the strict commitment requirements for patients receiving transplants, which demonstrates how involved family members are in the healthcare experience:

“So I am always insistent that we have at least one support person here because if they can't bring a support person with them we have a problem, they must have at least one dedicated person, sometimes I will get you know, four family members scrunched in here along with the patient {Laughter}. Yes, I have done it. We have to have one person here

so that I can say to them “are you the person who is going to come here with them for the biopsies?” and if they are not, if they say “I am just coming here for today” - so who else is going to be coming here with you and I want names. I don’t want them to just say a cousin, it has to be like a particular cousin who they can name that they know. So, and then I would ask them to bring that person to the next interview, we always want the primary and a back-up in case they get sick or can’t come in for whatever reason.”

(Betty, Case 1 & 5)

“Whoever is important and often the same son or daughter will come in with the patient, but sometimes they have a network of children that bring them in {Laughter} because it’s a big job.”

Greg (HCP, Case 4)

The “big job” of being a caregiver is informal and often unacknowledged within the current healthcare system. However, the functioning of the biomedical system depends heavily on the support of unpaid family caregivers. Not only do these caregivers have responsibilities managing the patient’s health, if they are the SDM they may also have to make challenging healthcare decisions on behalf of the patient. This involved not only determining the “right” decision, but making a decision based on what the “patient would have wanted” as Christopher highlights:

“A lot of times what patients express is not concrete enough or specific enough to have clear applicability so, if people use phrases like “if I should be near the end of my life” it’s not clear what that means. I am sure you are familiar with the literature on this. But it does provide a kind of reference point that we can refer family members who are decision makers back to, to help them, guide them and reminding them that what we’re really asking is what you think this patient would have wanted, not what you would want for yourself.”

Christopher (HCP, Case 5)

Not only did SDMs have the responsibility of making decisions in challenging situations, their involvement was often limited to a single decision: determination of resuscitation status. Because of this, SDMs lived with the consequences of making “wrong” decisions (Betty, HCP Case 1) when the arrangement had set them up to make a bad decision either way: either they chose not to resuscitate and “kill” their loved one (Rose, HCP Case 3), or they chose to resuscitate and expose their loved one to potentially painful and futile treatment. This was highlighted by Rose, who relayed a story regarding the son of a patient she cared for who had recently died:

“Recently I had a patient that passed away. The son actually was the SDM, and they [patient and family] could not make the decision. They don’t want to talk about it because of the culture thing right? Then when it actually happened – he had another episode of VT [ventricular tachycardia] - the son was there present and witnessed the beginning of the resuscitation. They asked him, he had to make the decision, right? He asked “what do you think?” and they explained the outcome wouldn’t be good if he responded, so he made the decision okay, let’s just stop. But then it’s left to him - yesterday he actually came by here and made the comment that he cannot live with it, trying to figure out whether he is actually the one that killed his father. I said no. I explained you shouldn’t think this way. The outcome wouldn’t have been good, and we talked about it, right? And, also he said quality of life is a big thing for him. You can see that he wouldn’t want that kind of life. He said yeah, I understand, but you always have this “what if” - what if we continued for longer maybe he would survive right? So, I don’t even know what to say, because I know he’s intelligent and he understood that’s why he made that decision, but on the other hand, we’re not the ones who are going to live their lives right? And then he had that guilty feeling right? I feel awful actually for him. He actually said you know, in the back of my head I just thought maybe I was the one who killed him.”

Rose (HCP, Case 3)

Betty echoed this by outlining how SDMs “feel really nervous” making decisions and that “they are going to torture themselves for the rest of their lives” if they make the wrong decision:

“I always say to people that you can have someone identified as your power of attorney but in my experience, when the time comes and somebody has to make a decision like that, they feel really nervous about doing it and, and feel like whatever they say is going to influence the outcome for their loved one, and if something were to happen then they are going to torture themselves for the rest of their lives. “What if I had said X or what if I had said Y, would things have been different?” So, I always remind people that even though there’s somebody who actually has to utter the order, that very often people feel more comfortable to discuss it with important people in the patients’ life so that they don’t carry the burden of that sole decision. But ultimately, they have to feel comfortable with it because legally the physicians have to do whatever that person requests. People often do that [joint family decision making] because they don’t want to carry the burden of maybe making the wrong decision.”

Betty (HCP, Case 1)

This begins to illustrate the extremely challenging nature of decision making, and how the rational, individualized model does not account for the emotionality and burden of those who are responsible for determining resuscitation status on behalf of someone they love. Betty’s and Rose’s discussion of the challenges faced by family members making resuscitation decisions illustrates how for family members, resuscitation was a moral choice, not a medical choice

(Walker, 2003; Peter & Liaschenko, 2006). Families were deciding if the patient would benefit from resuscitation, and as an SDM, if they were choosing not to resuscitate their family member, this could take multiple social meanings, such as the idea that “you don’t want your family member around”, as discussed by Nathan and Sarah (Patient and family, Case 1):

Tieghan: What specifically were important factors in thinking about whether you want to move forward with it [heart transplant] or not?

Nathan: {Long pause} Well... just living I guess is the primary thing and I think that even though the family was leaving that choice up to me, they probably would rather have me around. I don’t know why. {Laughter}

Sarah: Yeah, we wanted you around.

This excerpt from Nathan and Sarah’s interview demonstrates how decisions were constructed in family life, and the way people made decisions based on what was best for the family. Families were expected to “want” to have each other around, so there were very negative consequences for the morality of those who were required to make decisions that contradicted this sentiment, even if it was in the best interest of the patients themselves. This was relevant because this responsibility of family members, as well as the potentially negative impact that substitute decision making can have on family members, is not addressed in the dominant discourse surrounding the benefits of ACP and the way interventions are designed. This situation highlights the way that morality exists in practices and relationships (Walker, 2003; Peter & Liaschenko, 2006) and the role of these relationships is especially relevant when considering the impact of decisions regarding life and death. Within this study, participants experienced autonomy within a relational context; their decisions and desires were shaped by their relationships, their social roles, and the responsibilities they held to their families and to others (Mackenzie & Stoljar, 2000; Sherwin & Winsby, 2011). The experience of participants was very different than the rational and atomistic viewpoint that is portrayed by traditional individualized theories of autonomy that focus on rational decisions motivated by self-interest.

## 35 Autonomy is Experienced Relationally: HCP Roles and Responsibilities



The participants' experience of autonomy was also shaped by the opportunities that were available to them to access treatments and develop autonomy competencies (Meyers, 1989). Opportunities were often based on relationships with individual healthcare providers and were shaped by the dynamics of these professional relationships (i.e. HCP knowledge of transplant candidacy, HCP comfort referring to palliative care, HCP willingness to provide treatment outside the standard of care, or tailor guidelines to fit individual goals, etc.). Healthcare providers clearly felt that they had a role to support decision making, and specifically to support patients to make the decisions that they were comfortable with. At the same time, HCP were quite aware of the power dynamics present in their relationships with patients and families and often used this dynamic to make sure that patients made the decision that providers thought was "best".

### 35.1 Opportunities Depend on Relationships with HCP

Due to clinicians being the "gatekeepers" of information and opportunities, their training, expertise, comfort, and experience all shaped the opportunities that were available to patients (Meyer, 1989; Sherwin & Winsby, 2011). Whether this meant being referred for transplant, being referred to palliative care, initiating ACP conversations, or facilitating other aspects of care, the opportunities that were available to patients were dictated by their providers' individual tendencies, education, and preference. As Tracey (Nathan's wife, Case 1) noted, even though she was an experienced nurse she did not realize her husband could be considered a candidate for a transplant until it was brought forward by a new fellow they had been working with:

"I did not even realize he would be a transplant candidate - I thought he would not be. So, nobody had even discussed even consulting transplant. But thank God we had a fellow who said "why has he not been referred to transplant?" She just finished her transplant rotation in Toronto and I said "I never thought he would be a candidate," - basically nobody overtly said it, nobody talked about it. So she goes "I am going to refer him right away," so she referred him to Dr. Yung and we saw her. It was like two and a half weeks afterwards and we probably hit the window with about a month left. If he had been a month longer before we started doing all of this stuff, I don't think he would have had ended up with a transplant.

Tracey (Nathan's wife, Case 1)

Here, Tracey clearly attributed the opportunity to be considered for a transplant, and even Nathan's ability to receive the transplant, as being a direct result of working with a specific

fellow that occurred by chance. She noted how “nobody” in their usual care team talked about this option or even considered consulting the transplant team. Kate (HCP, Case 1) corroborated the sentiment that despite the highly guideline-driven nature of cardiovascular care, the opportunity to receive different types of care (heart transplant, LVADs, symptom management through palliative care referral, etc.) was highly dependent on the care provider themselves:

“I think the main influencer is the clinician comfort level. Sometimes they might have a well-educated person who wants to have conversations or explore what EOL will look like and they [cardiologists] don’t feel prepared to do that, so they will refer them to me to have those conversations.”

Kate (HCP, Case 1)

Rose (HCP, Case 3) also discussed how the ability for patients to access ACP conversations is “staff-dependent” based on their comfort level. She also noted that this discomfort may be the result of HCP always working to “make patients better”, and, therefore, some HCP may be uncomfortable with their role in ACP as this may be construed as accepting the fact that HCP cannot make everyone “better”:

“To be honest it’s also staff-dependent too, right? And some staff - more even for CCU [cardiac intensive care unit] right - they don’t advocate for this kind of discussion. But some staff are not....they’re a little bit more reluctant to have this kind of a conversation or not feeling comfortable right? And as I mentioned and because we have said we are in medicine, we’re nursing, we’re trying to help make them better right? That’s our main goal right? It takes time to change.”

Rose (HCP, Case 3)

Finally, Christopher (HCP, Case 5) added to this sentiment by highlighting that it was not necessarily patients who were uncomfortable with ACP conversations, but rather healthcare providers who were actually the ones who avoided conversations regarding complications and mortality:

“Yeah, in transplant particularly among, I would say an older generation and particularly amongst surgeons there’s still, I guess, I would call it a “lingering belief” that we want to always give patients hope and do everything we can, and then somehow would undermine that kind of therapeutic alliance if you start discussing things that could go wrong or situations in which the transplant is not working. So, there may be individual providers who aren’t comfortable having these conversations, but I haven’t seen it as much from patients themselves.”

(Christopher, Case 5)

Overall, patients' ability to access different forms of treatment, as well as participate in ACP was highly dependent on their access to different HCP, and the level of comfort HCP had with ACP conversations. These are examples of the way that social location and interpersonal relationships determine what opportunities are available to different people to pursue various treatment options and develop different types of autonomy skills (Sherwin & Winsby, 2011). These opportunities are shaped by the social locations of both patients and the HCP they work with throughout their illness experience, and, therefore, these relationships shape patients' ability to exercise autonomy within the constraints of those opportunities (McLeod & Sherwin, 2000).

## 35.2 HCP Power, Coercion & Control

HCP also exerted a significant amount of power by ensuring patients would consent to their recommendations and make decisions that aligned with what they thought was the best course of action. When following up with Han (Patient, Case 3) during his second interview, he and his wife Lily described how Betty, one of their HCP, continuously asked how likely he was to go forward with the heart transplant:

Tieghan: So, what did you and Betty talk about this morning?

Han: Same old topic.

Lily: How much percent have you decided to do the operation? You said like that.

Han: How many percent you think you would go ahead?

Tieghan: She asked that?

Lily: Yeah {Laughter}.

Han: This morning I told her 65% - oh, it's about your age. Then I said okay, maybe next time I meet you I am 85 {Laughter}. But anyways, just kidding, and I told her I promise her I will keep her posted, so I would let her know.

(Case 5)

Han's experience begins to demonstrate the subtle ways that HCP actions compelled patients into making the decisions that they thought were best, through inconspicuously applying pressure, such as Betty routinely asking Han when he would accept the transplant. Overall this

power dynamic contributed to the view that HCP and healthcare systems were responsible for the healthcare encounter and for dictating decisions regarding treatment. Kate (HCP, Case 1), also employed this method to benefit her patients; she stated that if patients were not self-motivated to participate in ACP, her strategy was to “put a guilt trip on them”:

“So, I explain it’s actually a gift to have this conversation to your family, so they are sure that what they did is what you want. So, if they are not going to be driven by their own [motivations], then I basically put a guilt trip on them.”

Kate (HCP, Case 1)

Although Kate realized her power in this situation by suggesting this was a “guilt trip”, she was employing her understanding of relational autonomy to motivate the patients she worked with. In her practice, she saw that patients might not align with the traditional, individualistic view of autonomy as rational individuals who were only motivated by their own self-interest. This type of self-focused logic is an especially weak way to motivate people to participate in ACP. Kate saw people as intertwined in relationships and responsibilities and highlighted these relationships as a way to encourage people to participate in ACP (McLeod & Sherwin, 2000). What she qualified as a “guilt-trip” was actually a highly nuanced approach to assessing and understanding people within their web of social relationships and using these relationships to benefit the family unit – the patient and the SDM (McLeod & Sherwin, 2000).

Finally, Nathan (Patient, Case 1) explained that he would bring his own medication to the hospital to take during admissions, because he was more familiar with his regime than the staff, and this avoided inevitable delays due to a lack of orders, trouble obtaining medications, etc. Even when patients were doing their best to be responsible citizens caring for and self-managing their health, their efforts were continuously undermined by professionals. For example, in an observational note from this interview, I recollected Nathan’s experience of leaving the interview with me. He knew many of the staff in the clinic and was being congratulated on looking so well after months of post-operative complications. As we were leaving, one of the most senior attending cardiologists casually mentioned to him that he was “over-doing it” by wearing a protective facemask because of his immunocompromised state. After we walked away from this interaction, Nathan was clearly very upset by this comment and turned to me and said:

“Overdoing it? If you’d had all the infections I’ve had, I don’t think you’d say I was overdoing

it.” This clearly demonstrated the power imbalance present and the way provider attitudes shape the patient experience and can undermine the small opportunities that patients do have to express their autonomy, such as choosing to wear a protective mask.

### 35.3 A “Debt of Gratitude”: Reciprocity Leads to Patient Obligation

Many participants discussed the notion of gratitude, or outright expressed deep gratitude for the care they received, which often directly related back to the high status of the institutions or the clinicians themselves. Betty (HCP, Case 1) noted that people generally felt “very grateful” that they were able to receive care at Hospital Centre A, and both Alvita and her daughters expressed that they were very grateful for their physicians and felt “so lucky” to be receiving care from their cardiologist. Despite this positive sentiment of gratitude, Christopher (HCP, Case 5) astutely noted that “good” patients are often required to demonstrate their gratitude towards their care providers, which can ultimately take the form of feeling obligated to accept treatment:

“I do worry that patients or family members may somehow feel like because they have been provided with such good care in the sense of people going out on a limb for them and investing a lot of time in them, that they may owe the surgical team something. It’s hard to really say how often that plays into EOL decision making, but I do worry that we may not be utilizing the best people to have these conversations. Patients may feel some of a debt of gratitude. It’s a very fine line because we want to enable people to benefit from transplant. At the same time, the entire field is very much oriented around rescue, and rescue isn’t always what advance care planning looks like for everyone.”

(Christopher, HCP, Case 5)

This sentiment was also clearly reflected in Han’s (Patient, Case 5) experience working with and receiving care from his providers. He expressed that this feeling of gratitude shaped his decision making and the way he reflected on his authentic desires when considering the option of accepting a transplant:

Han: Well, they make me feel like I am part of their family. Except they are the doctors, I’m patient {Laughter}.

Tieghan: Right, so you feel like they care about you.

Han: Oh yes, no objection. No, objection at all. That’s why I appreciate you folks, okay? {Long pause} And well, I told Dr. Yung to tell Betty [HCP]. Because Betty is really

concerned about me and she keeps saying she wants to see me put on the list before she is retired. And then she even told me whenever I need her to talk to me, she doesn't mind coming back here to see me. That's why I appreciate you folks, doing a lot for me.

Tieghan: But is that, like, some pressure on you, kind of?

Han: Could be. {Laughter} Could be... {Long pause} ...Yeah, and make me feel bad. So, I have to reconsider.

Tieghan: Feel bad because she is worried about you?

Han: Because everyone was so concerned about me, caring about me - from my family to the hospitals.... {Long pause} that's why I have to reconsider the whole thing.

(Patient, Case 5)

In addition to perceiving treatment as something patients were “lucky” to receive, the concept of receiving a heart transplant was constructed by participants such as Christopher (HCP, Case 5) as a “tremendous opportunity” and by Tracy (Wife, Case 1) as the “ultimate gift”:

“Yeah, it's very important to identify at what stage this could potentially skew someone's decision or cause distress, but because transplant medicine - and even before that dialysis started as a selective type of procedure where we wanted to focus on the best candidates because we were allocating a limited resource. I think there's this belief both among transplant clinicians and in the general culture that this is a tremendous opportunity being extended to people and it often is. But for some people it may not be an opportunity that makes sense, and I wonder if they are getting that message as well.”

(Christopher, Case 5)

Han also experienced the pressure to be a good patient and expressed some discomfort with this notion, and the responsibility that would come with accepting a heart transplant:

“I am lousy and I am not organized, that's what I can tell you. Now my wife keeps hounding me, but sometimes if she is too busy and I may forget that's what's really scaring me. I don't want - that's what Dr. Yung told me: “we gave you a heart and we don't want you to waste it and eventually garbage it” and I agree, that's why I am not 100% sure yet okay, but I follow the rules, okay. Whatever I am doing I will ask you folks because you folks are professionals.”

(Han, Patient, Case 5)

Han's experience reflected the dominant neoliberal tradition, as the intense burden of responsibility for personal health is downloaded onto individual citizens who must demonstrate

that they are “good patients” and responsible citizens. In this case, Han felt that he was held responsible for the success of the potential transplant, when in reality, he had very limited control over the outcome of the surgery or how the transplant would go.

Patients seemed to internalize the sentiment that they needed to be grateful for the care they received, and that by being offered the gift of care or treatment from their HCP, they were required to abide by specific rules to be considered good, responsible citizens who were morally worthy of receiving care. This was also demonstrated by Diane (Patient, Case 4), who although she discussed how challenging it was for her to attend medical appointments, felt that through a combination of gratitude, politeness, and HCP being in control of health situations, she would not request to tailor her appointments based on her preferences:

Diane: I am lucky having nice doctors like your doctor and all of the people who look after me.

Tieghan: And do you ever say: “I don’t want to come to appointments anymore?”

Diane: No, no, no. They know what’s going on. No, I do appreciate it, but I don’t know what else I can say.

(Case 4)

These cases demonstrate the limited power patients truly have in many encounters. If they are unable to request to tailor appointment schedules to suit their needs, it may not be reasonable to expect that they can tailor treatment options at the EOL to their needs and preferences. Overall, this highlights the intense role that HCP hold in the decision making process of patients and the way that interpersonal relationships and power dynamics influence the ability of people to be autonomous. By incorporating these types of social and political relationships as well as power dynamics, relational autonomy can be used to conceptualize this experience by recognizing the presence of constraining forces and provides an exploration of how factors such as power, gratitude, and obligation, can interfere with one’s ability to exercise autonomy by undermining one’s sense of self (Sherwin, 1998). In general, dominant social forces such as the power of biomedicine, as well as the interpersonal power imbalance between HCP and the desire to be seen as good and morally worthy may inhibit patients’ self-confidence at the various levels of autonomous decision making (McLeod, 2002).

## 36 Autonomy is Experienced Relationally: Social Location Shapes Decision Making

Social location consists of ascribed social identities (i.e. gender, race, sexual orientation, ethnicity, kinship status), and social roles and relationships (i.e. occupation, political party membership, familial positioning, etc.) (Grasswick, 2013). People's experience of autonomy was shaped by personal factors that made up their identity such as their age, gender, culture, personality, financial status and health literacy. These will each be explored independently in the following section.

### 36.1 Age

For Alvita (Patient, Case 2) and Diane (Patient, Case 4) who were two of the eldest study participants, age was seen as something that dictated treatment decisions and was extremely relevant to the discussion of treatment benefits. Gabrielle and Brianna (Alvita's daughters, Case 2) highlighted that if Alvita had been younger, she may have been interested in receiving chemotherapy to treat her cardiac amyloidosis, however she was not interested in going through that type of intensive treatment at her current age:

Gabrielle: She's a traveller, she loves to travel and she's been going about her business, she joins the center, she's been to Cuba about three times. At the community center that's part of their social thing they go on trips together, she goes for plays, and suddenly you know, this just hit her and all of a sudden, she is old. We never thought of her age until this year.

Brianna: There's two different kind of amyloid and when you are younger they use a chemo to treat all of that, but even if she was a little bit younger I don't think she would want to go through it. My mom would not go through that.

(Case 2)

Diane (Patient, Case 4) echoed this sentiment, as she did not see the point in invasive testing such as angiography because she did not see herself living much longer, and also did not have the desire to live much longer:

"They tested me for all kinds of things, he [cardiologist] wanted to have an angiogram and of course I had the test for that and my niece had to stay overnight and all that. Then I said: "I am not going to have that angiogram" - forget about it, at my age? Forget it. I also have now starting a breast cancer on my right side forget it, I said at this age what are you going to do with it. For what should I go through? I mean I can't live much



longer {Laughter}. And if I have to live much longer I will probably lose my marbles too like the rest of them here.”

(Diane, Case 4)

At the same time that age seems quite relevant, Daniel (HCP, Case 3) highlighted the variability between patients, and the fact that judgements cannot be made broadly based on age due to the different perspectives people have regarding their own mortality. He pointed out that treatment guidelines largely do not have age cut-offs, so although this should be factored into treatment conversations, it may not be routinely addressed because it has been excluded from guidelines. Despite the importance that Alvita and Diane placed on their age and how this factors into their decision making, Daniel (HCP) again highlighted that this is not necessarily the same for all elderly patients, and that again this must be examined at a personal level in relation to what the patient and their family value and how they understand mortality and death:

“A lot of older patients aren’t looking to avoid sudden death in their sleep, there may be an understanding they are going to die and that may be a good death and I think most people agree with that. Some don’t, but most do and so that sort of gets around the issue of well, are we really going to put a defibrillator on somebody who is 95 years old when like that’s the sudden death - but now we’re avoiding the death? And I have had that conversation with people and they are generally sort of are okay with that. I always start with “this is a morbid conversation but...”. I think there’s such variation in terms of what people expect and their preparation for EOL like I’ll have a 70 year old who is like nope, lived long enough I don’t care if I die suddenly, I don’t want a defibrillator not interested if I die in my sleep I am fine with that and I have 90 year old’s who are not.”

(Daniel, HCP, Case 3)

Patient participants in this study recognized that receiving healthcare and treatments was a physical burden. After a certain point in their lives, they did not see the pursuit of treatment as something that was worthwhile for them, however it was unclear whether this was explored routinely with their HCP in the context of treatment decision making, especially considering the lack of acknowledgement of age in many of the cardiovascular care guidelines.

## 36.2 Gender

Although there were more male HF patients (n=4) than female HF patients (n=3) in this study, the overall percentage of female participants was 71% (n=17) and 100% (n=9) of the family caregivers in this study were female. The sampling strategy for this study was purposeful in

order to achieve maximum variation in patient characteristics; this led to a highly diverse sample of patients, however a very homogenous sample of caregivers (middle aged females who were either spouses or daughters of the patient). This highlights the already well-known fact that caregiving responsibilities fall extremely unequally onto women in society, which is explained quite clearly by Gabrielle and Brianna (Alivta's daughters, Case 2) who although they are not the formal POAPC due to gender dynamics within the family, they are still responsible for healthcare support and decision making support:

Gabrielle: The history of Caribbean family is that the girls are low down {motioning under the table} and the boys are kings. So, her boys are her boys, very good to her in what they do for her and I have one brother that is very smart and he is the one, he is her number one son. So, he provides that aspect of it and we provide emotional help, the health - her two girls.

Tieghan: So, if there were healthcare decisions to be made if she wasn't feeling well you think it would be you two that would be making decisions?

Gabrielle: Yeah, it would us - he would come to us. Because he comes to us for everything. Yeah, he would come to us and ask us. If my brother, who is the one who lives with her, called one day and said "I can't wake up mommy," my other brother who's her number one son would say "call one of the girls."

(Case 2)

### 36.3 Socioeconomic Status

In this study, finances were often reported by participants as playing a role in the ACP process; having a higher socio-economic status and wealth was identified as a motivator to complete the legal aspects of ACP (such as a financial POA, financial will, etc.). Pam and Katharine (Patient and Daughter, Case 7) discussed how Pam's POA documentation was linked to the "corporation mapping" process of the finances of their family business, and that POAPC was a small piece of this process. Sheena (HCP, Case 7) also discussed how financial planning is a key way to access EOL planning, and that people tend to focus on finances when considering their "legacy and their bank accounts". This aligns with participants constructing ACP as after-death planning related to wills and burial arrangements, etc. that centre around financial responsibility:

"You reach a certain point in wealth accumulation where like a financial advisor will be like: "go out and get a will" but until people reach that point, and most people don't, it

seems like most people don't bother to get wills but again it's a personality thing. When it comes to sort of estate planning or advance care planning, I think one of the things that motivates people to do it at all is money. Like just in practice I think most people who tend to think about these things tend to be of a higher socioeconomic status right?

Sheena (HCP, Case 7)

Although personal characteristics such as “personality” (Sheena, HCP Case 7) and “being organized” (Betty, HCP Case 1) were highlighted by participants as factors that supported ACP participation, when further explored, these seemed to actually be coded terms for people with higher socio-economic status, as Betty (HCP, Case 1 & 5) later revealed through her focus on financial preparation, having “no debts” and the ability to access a lawyer:

“I think people who have done all that [POAPC] are prepared - they are the people who have saved money in advance, they are organized in terms of making sure that they have no debts or you notice that there are other aspects of their life that are taken care of you know? Or just made sure that they had insurance to cover their medication or maybe mortgage insurance. So they are the ones who have obviously sat down with somebody who said you should consider doing powers of attorney, and in those cases it starts off with power of attorney for property and then kind of part in parcel you have a power of attorney for personal care. So, they tend to be like really organized people. It doesn't necessarily mean they are intelligent so I wouldn't say people who are more intelligent, have that completed, it's more I think people who are organized would have that...they have met with a lawyer when they did their will and the lawyer may have said you know, we have done your will but let's also do your powers of attorney while we are doing it because they all go together as a cluster.”

(Betty, Case 1 & 5)

Sheena also acknowledged how the legal system doubly disadvantages those who may have lower socio-economic status due to their inability to access expensive legal services:

“That's true of the whole legal system - like access to justice was something that we talk about so often because lawyers are expensive, like stupidly expensive. If I was coming up with a novel living will document I would probably spend an hour or two on that - and I was extremely junior like I did not work for very long - my billable rate with \$300 an hour so that's a \$600 will right there if I took two hours. Talk about access to justice, who can afford? But the billable hour model and the way the law is set up is not set up to help people who need it, it's set up to help people who can afford it, which really gets me.”

Sheena (HCP, Case 6)

This demonstrates how the legal origins of EOL planning continue to shape the ACP experience, and the way that access to legal support for these processes can lead to inequities that favour the wealthy. In addition to finances being a motivator for patients to plan for EOL, having made financial arrangements seemed to be a point of pride for some participants, as well as a way to exert their control. Alvita (Patient, Case 2) discussed how she had already paid for her funeral, bought her burial plot and arranged her financial will. Her daughters described how “everything is done” and that by arranging her finances, Alvita was maintaining control of her life and lessening the burden on her children. Judy (HCP, Case 6) also highlighted that by buying pre-planned funerals and arranging for cremation and burial plots, her parents were “just trying to be responsible and think ahead.” Participants felt that making financial plans for EOL was a way to be responsible and proactive and ensure that arrangements were made in order to lessen the burden on family members when they died.

## 36.4 Health Literacy

Patients in this study were highly health literate; multiple patients had HCP in their families who supported their illness management and health decision making. Andrea (HCP, Case 4) highlighted the fact that many of the residents in her assisted living facility understood what CPR was and she attributed this to the health literacy of the residents or their family members:

“But, as I’ve said, most know what CPR is, and I would say many of them have families that are in the medical field - that’s why it helps in dealing with doctors, surgeons. Some of them, or most of them have medical histories, they were in the medical health field.”

(Andrea, HCP, Case 4)

The role of health literacy in supporting patient autonomy was also identified by Marie (HCP, Case 1):

“It depends on their health literacy. I find, people who are very, very health literate and realize the repercussions of something complicated, or complex clinical situations they would probably say “we don’t want any of that” and then the people who are not as health literate would say “just do everything,” because they just don’t know.”

(Marie, HCP Case 1)

Here, Marie highlighted the way that health literacy allowed people to make “better” decisions because they understand the repercussions of receiving complex therapies and interventions. Despite the view from HCP that highly health literate patients may be more prepared to stop treatment when it becomes too complicated or risky, almost every case in this study had a very explicit example (if not more than one) of patients and family members doing the opposite and advocating for themselves in order to obtain the care that they deemed necessary, such as consults, referrals, admission to hospital, etc. These acts of self-advocacy and resistance demonstrated opportunities in which participants felt they held agency over their situation and were able to make an impact in their health trajectory. Gabrielle (Daughter, Case 2) and Brenda (Wife, Case 6) also both discussed ways that they had advocated for their family members:

“I’ve worked in critical care for over 30 years, and my brothers consult me with everything. If one of their children does gymnastics and the next thing I get “can you meet us at the hospital please?” You know, I am a very bossy kind of person {Laughter}. I am a nurse. I want to see all of my family’s blood work. I can read them, please let me see them. I can make a decision and I can advise my family based on what I know. For the most part it’s been very good, even when she had her heart attack I followed them all the way and I said to the doctor “I am coming in, you are putting in the stent I am gowning and coming in,” and they’re good you know?”

(Gabrielle, Case 2)

“Well, he wouldn’t have looked after himself if I wasn’t the aggressive one. When the prostate came, he was devastated, and I says well, we handled it once, we will just handle it full tilt with this one. I said to the urologist “can we get a referral to Hospital Centre D?” And because I worked in pharmacy, I was not the pharmacist, but I worked in pharmacy, I knew from the drug that the urologist was giving him was the last resort. So two weeks later we went back into the urologist and I says “can we get a referral to Hospital Centre D?” and he was lucky he had Dr. M, she was a female, she was the head of the department, and she travels all over the world to lecture.”

(Brenda, Case 6)

Cases 1, 2, and 6 all had one major commonality: the SDMs all worked within the healthcare field. In Case 1, Tracey (Nathan’s wife) was a nurse with a critical care background. In Case 2, both Gabrielle and Brianna (Alvita’s daughters) were registered nurses, and in Case 3, Brenda worked in pharmacy. Each of their experiences highlighted the way that “insider” knowledge and experience in the healthcare system as professionals supported their ability to advocate for themselves and their family members and exercise agency in challenging situations. These

examples demonstrate opportunities they had to develop autonomy competencies, and the small ways that patients and their family members are able to exercise autonomy throughout the illness trajectory. This experience of Diane, who was not happy with the care received at the assisted living facility and sought out her own family doctor, resonated with the experiences of other participants who took advantage of moments such as this where they could advocate for themselves and take control:

Diane: But of course the doctor here, he treats us general like all like the old cookie ones. I had infected blood, but to them it doesn't mean much – “take your time, stay in bed.” Well I would call my own family doctor back I said “Dr. Williams, would you like to take me back because this is a different system here - they are a little slow for me.” So he took me, yes of course.

Tieghan: So, here the doctors don't attend to things as quickly as you would like?

Diane: They do because in general, the people don't even know what's happening. It's just like a mental hospital here.

(Case 4)

Patients and caregivers understood their role in taking personal responsibility for their health and ensuring that they had access to the type of care they thought they required. Therefore, opportunities for agency were primarily connected to seeking out and advocating for more treatment, or appropriate referrals, as opposed to making specific treatment decisions, which was seen as under the purview of the healthcare team.

## 36.5 Culture and Spirituality

In many cases, participants highlighted the role of culture or spirituality in relation to both healthcare decision making and EOL planning. Brianna (Daughter, Case 2) highlighted how both as a daughter of a Caribbean woman and as a healthcare provider, she felt that Caribbean people are more likely to take control of healthcare information and “go out and seek knowledge” in order to prepare and plan for future decision making. Marie (HCP, Case 1) echoed this by noting that occasionally her patients were resistant to having EOL conversations. She partially attributed this to culture by stating that “sometimes it's cultural, and sometimes you just get a feel that they are just not ready”. Rose (HCP, Case 3) explained this in further depth; as both a

HCP and someone of Chinese descent, she explained the way that certain cultural beliefs may affect the ACP process:

“Sometimes they say “no” and also patients’ cultural background right? I have another patient and the son said “you know, they don’t even want to talk about it [death] because this is bringing them bad luck.” It’s for my own culture too, for elderly Chinese, they say: you talk about death, it’s bad luck right? You are wishing a bad result right?”

Rose (HCP, Case 3)

Christopher (HCP, Case 5) also noted this experience in his practice:

“The other thing I would note is that there are some patients who come from cultural backgrounds where it does seem to be taboo to discuss death or even bad surgical outcomes because there seems to be some kind of a belief that it becomes a self-fulfilling prophecy and that can be a challenge to good advance care planning.”

(Christopher, Case 5)

Despite these perspectives from Rose and Christopher, the two Asian patient and family member participants in this study who originated from China (Han and Lily) did not seem to hold this same belief and were quite open to discussing the potential complications and negative outcomes from surgery and the possibility of death. This begins to highlight the way that approaching ACP through the lens of important relationships as opposed to specific cultural or religious beliefs may be helpful or more fruitful. In addition to culture, being part of a specific religion was highlighted as a relevant factor in the way patients consider EOL planning and decision making. Although the role of religion can play an important role in each patient’s personal experience, both Christopher (HCP, Case 5) and Rose (HCP, Case 3) outlined that they had learned not to assume anything about a patient’s preferences based on religion alone:

“Another thing I have learned, is not to pre-judge or to be very careful about reading into references to religious faith or religious motivations because they can mean different things to different people. A patient themselves might identify as Christian and say they are content to meet their maker at any time, another person may use the exact same language of being a Christian and use that to link to a belief that they should do everything possible to extend their life and let God decide rather than a human being decide when it’s time to meet their maker. So it, we have to be very careful a) not to read the wrong things into religious references but b) not to assume that we know what a patient’s religious commitments meant to them.”

Christopher (HCP, Case 5)

“And then there are people who said you know what, if they are religious they said that okay, God give me life, I should live as long as possible you know. Then there are some people who say okay, God give me my life and when he says it’s ready to go, they just take me right? So, they are different interpretations, right?”

Rose (HCP, Case 3)

Both Christopher and Rose noted that religious beliefs can be incorporated into people’s lives in various ways, which can lead to completely different interpretation of the same type of religious values. They highlighted the fact that although religion may be extremely important to people, it may not impact their ability to engage with the ACP process, as it depends entirely on how the religious values are interpreted. This continues to demonstrate the way that social location is relevant, yet individual variances may not provide a complete account as to why some people may be more or less able to engage in the ACP process, as both participants who identified as religious and those who did not were equally engaged in the process.

## 37 Autonomy is Experienced Relationally: Broad Social Forces Impact the Experience of Autonomy

Traditional conceptualizations of autonomy tend to isolate autonomy from the broader social locations of people and from the broader context of healthcare decision making. This study demonstrates the realities of how personal autonomy cannot be isolated from the social, political, economic and relational contexts that shape people’s lives. People’s experience of autonomy was shaped by social discourses such as ageism, individualism, gender oppression, self-management, and neoliberal ideology.

### 37.1 Ageism: The Connection Between Moral Value and Age

In addition to neoliberalism, ageism was a strong social force that is highly influential in the construction and prioritization of ACP. Despite the fact that ACP is a process that should be relevant for “adults at any age or stage of health” (Rietjens et al., 2017), there was an underlying discourse of ageism that targets ACP specifically at those who are older. Healthcare providers and governments want elderly people to make the “right” choices by completing ACP documents to reduce intensive interventions for these populations at the EOL. In this study there was a sense that when patients were younger, ACP was not relevant because “everything possible [should] be



offered” or they were “not yet at that point” to discuss ACP because patients might have had young families or significant financial responsibilities, as discussed by Betty, Tracey, and Rose:

“And you know, we, they might have more of an effort if they have younger children obviously then they want everything possible to be offered to power of attorney to make for them...”

Betty (HCP, Case 1)

“Yeah, so in his case I think it’s a little bit different like everybody almost wants to kill you with kindness. It’s a little bit of a different environment I think than your average person. But there wasn’t a lot of talk about that, of course with his age it was like well yeah, you know, full code, we will do everything, all that kind of stuff.”

Tracey (Nathan’s wife, Case 1)

“I say nowadays lots of people they know exactly - we have patients that even at a younger age they come in with a living will or something right? Yeah, sometimes we don’t have to have another conversation, we don’t think it’s at that point yet right? And to say “definite no” to resuscitation, but you are only 40 years old right?”

Rose (HCP, Case 3)

If young patients did not want extensive treatment (i.e. ICD or resuscitation) this was seen as the “wrong” decision by healthcare providers and was not easily accepted, as was demonstrated by Judy (HCP, Case 6) and Rose (HCP, Case 3), who expressed their discomfort when they worked with young patients who did not want interventions despite medical recommendation:

Judy: So, we just had a conversation with a 20-year-old who survived cancer, but he got sick and he is feeling better, but his ejection fraction is like 15%. So, we’re trying to say we’re worried that your heart is not going to recover on more medical therapy because you already were on good stuff and we really think you should have an ICD and he says nope, I just want to live my life. And that’s in the context of his father sitting right there with him.

Tieghan: Oh wow, okay. And how do you approach that going forward?... {Long Pause} Do you just try to bring it up later?

Judy: We would yeah. Again, again. And then we document that you had these conversations and that the patient really declined at this time, sort of thing.

Comparatively, when patients were older and had fewer social responsibilities, there was a different assessment of the moral or social value of their lives and the value of keeping them

alive with intensive interventions. Rose (HCP, Case 3) seemed to assess the moral value of some patients based not only on their age, but on their cognitive capacity. She distinguished between seniors who are “sharp as a knife” and able to care for themselves or enact self-management, versus seniors who “need lots of help” and were dependent on their families:

“Yes, because we have lots of senior people right? And you know, some of them are amazing and they are in their late 80s. They are just you know, sharp as knife right? Yeah, but there are people you know, patients they need lots {Laughter}...and they rely on family.”

Rose (HCP, Case 3)

Expanding beyond ACP specifically, patients experienced ageism in their daily lives and interestingly in Diane’s case (Patient, Case 4), it was most obvious to her when she went to seek healthcare in an acute care setting and her concern was not adequately addressed. This was contrasted with her experience at another hospital that has more familiarity with older adults, and in this setting, Diane felt as though her problem was adequately addressed and she was taken more seriously. She made the connection between HCP realizing her advanced age and their resignation to provide very limited care:

Diane: The only thing Hospital Centre A, when I walked in there first and they heard my age, they gave me only a stronger pill and sent me home. Hospital Centre B was different. They tested me out oh my God, it was just fantastic. For everything, they, they tested me for everything.

Tieghan: And at Hospital Centre A they just sent you home?

Diane: Hospital Centre A was a bit...yes. Well, naturally, what are you talking? What do I do with an old guy like that...

(Patient, Case 4)

Finally, Daniel highlighted the limited data available to make decisions regarding HF therapy for older adults. He characterized this ageism in clinical trial enrollment as related to the motives of the drug and device companies to “intentionally make it opaque” so it is challenging for HCP to know who will benefit and at what age various treatments may no longer be beneficial. This “opacity” leads to higher rates of device use and therefore higher profits for the companies:

“We know that the data for older therapy is more modest. It’s a little bit opaque to find out exactly how many older patients with comorbidities are studied in clinical trials, like they usually have ranges and we spend a fair bit of time saying listen we don’t really know for sure. We think this works. We have some subgroup analysis but intentionally the drug companies and the device companies intentionally make it opaque to figure out exactly what kind of patients are enrolled because they would rather have over inclusion than under inclusion and so that’s the kind of data that we’re stuck with.”

Daniel (HCP, Case 3)

This is a direct example of the way ageism functions in our current society and that it is not seen as worthwhile for drug and device companies to provide analyses specifically for older demographics of patients. These choices then can influence the way decisions are made in healthcare and can potentially lead to negative health outcomes due to this lack of data. Overall, ageism was a pervasive social force that influenced many aspects of the ACP process, specifically in terms of the ways patients self-evaluated their desires and the risks and benefits of various pathways, as well as the way other people evaluated the social value of patients based on age.

## 37.2 Neoliberalism: The Power of Individualism and Independence

Throughout the study and in line with neoliberal ideology that perpetuates ideals of individualism and independence, participants constructed independence as a positive trait and dependence as something that is negatively construed. Below, Gabrielle (Alvita’s daughter, Case 2) emphasized how her mother was independent and this level of independence made her morally “good”:

“She was an active gardener, you should see her garden and now she can’t do it. That is more bothering my mom, not the medical aspect of it, the independent aspect - she used to do for herself and now she has to be dependent. And you know, she doesn’t go well with that. She still wants it done her way, and she is not dependent on the system, not anything like that. I was surprised that my mom was so independent in her after-life planning. Yeah, that was shocking for me even, because she just told us “don’t worry about me” and every month I have to take her and she pays her insurance everything is done, she is done, done, done, done, she is good.”

Gabrielle (Daughter, Case 2)

Being independent of others and independent of support systems (such as government assistance) was seen as an inherent good, and the inability to care for oneself was constructed as a negative

trait. In addition to shaping the way problems are constructed and prioritized at a broad level in current society, neoliberalism restricted autonomy through relationships of power within the healthcare system. Patients felt that they needed to be good, responsible, independent citizens in order to receive treatment; this meant they needed to “follow the rules” as Han (Patient, Case 5) noted, and be grateful for their care by accepting the treatments that are offered to them. Diane (Patient, Case 4) was also familiar with this and expressed how she “hated” that she was aging and dependent on others:

Tieghan: So, you have a niece living in New York?

Diane: That’s all of the rest of my relatives. I outlived them all. 98. I hate it.

Tieghan: You hate it?

Diane: Yes, of course.

Tieghan: Why? Tell me more?

Diane: I am also independent, and now of course I didn’t realize I would get so old and that I would need help and I would have to get dressed in the morning, undressed at night.

Tieghan: It’s a lot of work.

Diane: It’s so difficult.

(Case 4)

Neoliberal ideology and politics of austerity are current realities of the Canadian healthcare system. These discourses have shaped the way ACP has been constructed as an individual-level problem rooted in personal autonomy, that patients who were good neoliberal citizens would participate in and good healthcare providers would support. Neoliberal rationality emphasizes autonomy and the capacity to care for oneself, and shifts away from the idea that the state is responsible for the health and well-being of its citizens, towards the notion that individuals hold the responsibility to protect themselves from risk (Petersen, 1997; Tronto, 2015). This can be connected to the push for “responsible” citizens to participate in ACP. Daniel (HCP, Case 3) expressed his frustration with the way the problem of EOL care and planning has been

constructed and forced us to ask why ACP has become a priority in our current society, and what sort of broader social and economic considerations may be shaping this issue:

“I guess the question is: what’s the problem we’re trying to address? Like who’s complaining? I mean we all think that we should have palliative care and we have all seen deaths that we’re like “oh we should have avoided this” but are there families and patients that have been like... where’s the issue, what are we trying to improve? There’s always the question. Like what family is like “if I would have known I never would have put my family through this”? People say that sometimes off the cuff but was there any intervention that would have been possible? Like what are we aiming to correct here? I mean yeah, it’s nice to have a notion that everyone should have an advance care plan, and everyone should know this. Is the goal - are we trying to save money or are we trying to prevent med-surge ICU admissions for the last 10 days of their life? I mean maybe, and are we going to do that without pissing off people? Maybe that’s the end goal I don’t know. I think that’s a problem right. We all know that most of the healthcare dollars are spent in the last part of life and if we can chop that part off I think everyone in society would benefit, but you probably have to do that carefully like with this kind of thing involved. But economics aside are there patients in the last 10 days in ICU saying “we should never have gone down this road” - is that happening? I don’t know.”

(Daniel, HCP, Case 3)

Daniel’s questions surrounding this issue underscored the tensions that develop when practices such as ACP are framed as individual level responsibilities when they may be created as the result of broader social, political and financial forces. He astutely highlighted that a large amount of healthcare dollars, in the publicly funded Canadian system, goes towards intensive care at the EOL. He understands ACP as a response to this, with the goal of reducing spending, but being branded as something that is supposed to empower patients or solve patient “problems” that may or may not exist (such as the desire to have more control over EOL decision making). These discourses which underpin ACP tend to overemphasize the role that individuals hold in maintaining health by emphasizing the self-management of risk and promoting self-care and empowerment, especially in chronic illness management, under the assumption that all agents have equal abilities to enact self-care strategies and engage in ACP (Petersen, 1997; Tronto, 2015). This discussion highlights the way neoliberal ideology can turn moral and ethical concerns (i.e. is it just to use this amount of healthcare dollars at the EOL) into technological concerns regarding the documentation of advance care plans. As a HCP, Daniel (HCP, Case 3) was wary of the goal that ACP purports to have (empowering patients and supporting their autonomy) and

instead saw it as a strategy being pushed to reduce healthcare spending for a certain demographic of patients and was rightfully skeptical of the motives of the ACP movement.

### 37.3 Medicalization of Death and The Social Avoidance of Dependence

A broader implication of the benevolence of biomedicine is that this discourse perpetuates the medicalization of death and social avoidance of the topics of dependence, vulnerability and decline, even for HCP who care for patients with advanced terminal illnesses, such as those who work with HF patients. There was significant tension surrounding this topic, as Judy (HCP, Case 6) seemed to place the responsibility for this type of avoidance or denial onto patients and family members themselves, while Tracey (Wife, Case 1) expressed frustration with physicians' lack of communication skills surrounding death:

“I think sometimes they [patients] are not ready. They are probably in a phase of denial or maybe their family members are in a bit of denial or they just don't want to have the conversations, not yet.”

Judy (HCP, Case 6)

“Yeah, and that's actually why I stopped working in the big ICU. Just too tired of awful never-ending keeping people alive and just non-stop. It's awful, and they die eventually anyways and it's just awful to watch. Feeling helpless because you were getting resistance from attending physicians or family, and a lot of it was communication which is kind of what your whole thing is about. But it's difficult to watch people suffer like that when it's not necessary. You know, you don't let pets suffer like that. And it's because people don't know how to talk to people, right? I think a lot of physicians don't know how to talk to people or don't know how to talk about death.”

Tracey (Nathan's wife, Case 1)

Interestingly, Peter (Patient, Case 3) also acknowledged that he thought it was time to discuss EOL with his wife, but his wife would “rather just avoid talking about it,” meaning that he did not have the opportunity to share his own thoughts and feelings on the topic. This highlights how the ability to be truly autonomous and express personal desires is also dependent on (and limited by) the relationships people are in and the emotional openness of SDM:

Peter: Yeah, and it's [resuscitation] not really straightforward, it's not a yes or no, but that I haven't looked into it enough to really know where it is. But I know she [wife], I

am quite sure she would rather just avoid talking about it, whereas with myself, it can be time to talk about those things. People don't like to admit that you are going to die someday.

Tieghan: So it sounds like you have thought about this quite a bit. Have you had any of these conversations with your wife?

Peter: Hmm, no we have never been, she never wants to discuss those things...we got ourselves a puppy about a month ago.

(Patient, Case 3)

Participants often placed the responsibility for death denial or avoidance on others, however, when Peter (Patient, Case 3) was pressed further about his conversations with his wife, he redirected the conversation by stating "we got ourselves a puppy". This demonstrated the role the puppy played both literally and figuratively to distract from Peter's advanced illness, to provide companionship for his wife, and to provide them with something joyful to focus on as opposed to focusing on death.

This discussion highlights an extremely important point about ACP that is often glossed over – that it is entirely dependent on having an SDM that is open and willing to discuss the intimate details of EOL care and face the death of someone they love most in the world. This takes a combination of a deep understanding of the illness and the confidence to discuss something that is rarely addressed in society. The discussion also involves the added horror of having to imagine the demise of the person you love and having to remove all emotion to have a rational conversation about care preferences. From this perspective, it is clear why this may be something patients and families are unable to do, even if the patient is entirely "ready" to die, as some of the patients in this study, such as Marty (Patient, Case 6) and Diane (Patient, Case 4), both expressed.

Tieghan: So, you know that moment Brenda mentioned to me at the beginning about where you said: "I'm done, I am ready to meet the Lord."

Marty: I am. Any time.

Tieghan: Any time?

Marty: Any time.

Brenda: His left ventricle valve is not bad enough to do surgery. But the nurse in CCU said to me that as long as he keeps his fluid down that will work okay, not perfect, but it's working okay. And you know, how it's got to be a certain percentage before they will do, whether it's the stent or the same thing with the valve, so, we've been successful. He is keeping his fluid under control. Yeah, it slowly, slowly came down, at first when he came home like from the ankles down but that's okay, we got that stabilized.

(Case 6)

At the beginning of our interview, Marty (Patient, Case 6) discussed how he was “ready to meet the Lord” at any time, and acknowledged that he may have limited time left to live, but when I brought this up again, the conversation was quickly redirected by Brenda, who wanted to focus on the medical management of his condition and what they were doing to keep him alive and medically stable. This aspect of working with a substitute decision maker is something that is relatively unacknowledged in the push for ACP, which reduces these challenging interpersonal dynamics to a technical process of “discussing values, wishes and goals” with an SDM, without acknowledging the deep emotionality of this experience or the social forces that may influence this experience. Betty (HCP, Case 1) also highlighted the anxiety that accompanies these conversations:

“A lot of people feel understandably anxious. There's a lot of fears that they otherwise may not have brought up. There's that thinking about “if I speak about it it's going to happen.” Hmm, we do talk about issues around death, and it's interesting how people have trouble saying death - they will say you know, if something should happen to me if you know, things go the other way, if it's not successful...obviously we're getting right down to the nitty gritty of somebody's mortality and it's quite close to home for them to be able to talk about it in such a way that it almost an immediacy about it you know?”

Betty (HCP, Case 1)

“No one thinks they are going to die. No one thinks they are going to get injured and need an advance care plan. That's a reality they are just not ready to face. That's a cultural problem.”

Sheena (HCP, Case 7)

Betty and Sheena both outlined the overall social fear of discussing death, and the role that language plays in perpetuating the avoidance of death. Additionally, Sheena highlighted that the ability of people to avoid the reality of death and acknowledge their own mortality is a part of a broader “cultural problem” that does not generally allow for death acceptance. Overall this



demonstrates the important role of death avoidance within our culture and the way it may impede the ACP process at a broad level.

## 38 Conclusion to the Results Chapters

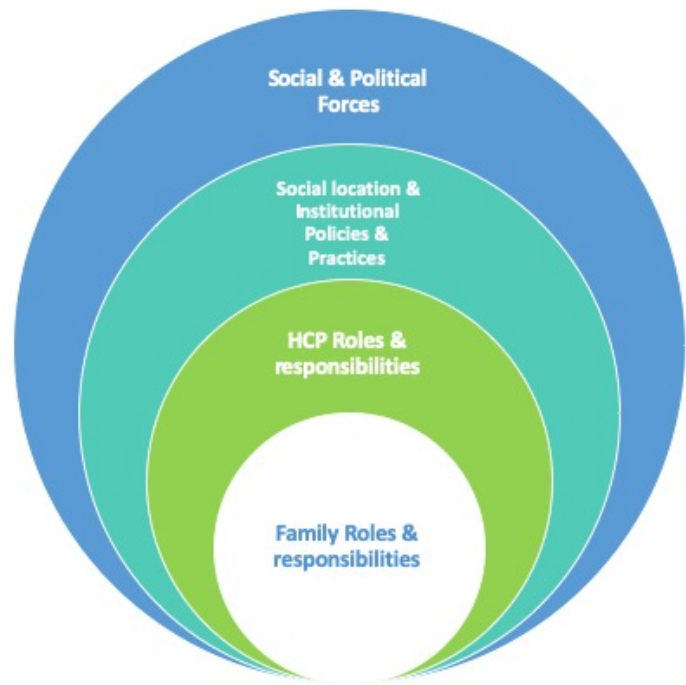
In these chapters I have answered the following research questions:

1. How do people living with heart failure understand advance care planning?
2. How do people living with heart failure express autonomy when participating in advance care planning?
3. How does social location mediate heart failure patients' experience of autonomy and participation in ACP?

To accomplish this, I outlined the various ways that ACP is understood as external to treatment decision making within the current biomedical landscape, with a specific focus on the power of the legal model and the understanding that ACP is a personal process that takes place outside of the clinical encounter. Following this, I outlined how the experience of autonomy in advanced HF is incongruent with the dominant individualistic approach and that it, instead, is a relational experience. Finally, I concluded with a thorough overview of the various ways that autonomy is experienced relationally within the ACP process, by examining the role of interpersonal relationships and responsibilities, the role of power dynamics, and the ways social location and broad social forces shape decision making and influence autonomy. In the next chapter, I will build upon the previous three results chapters in order to discuss the findings of this study by situating these results within the broader landscape of current ACP research.

Figure 4: Autonomy is Relational

**Key Finding #3:**  
**Autonomy is Relational**



**Figure 4:** Autonomy is deeply connected to family roles and responsibilities, relationships with healthcare providers, social location and social identities, and is influenced by institutional policies and practices as well as dominant social discourses such as ageism, individualism and self-management that stem from neoliberal ideology.

## Chapter 9

### Discussion

#### 39 Introduction to Discussion Chapter

In this discussion chapter, I consider the findings of this study in relation to the broader scholarly literature while continuing to draw on the main theoretical perspectives of feminist ethics and relational autonomy. Overall, there are three key findings that resulted from this exploration of ACP with the HF population. First, ACP was understood as external to treatment decision making within the current biomedical landscape by both patients and family members. A strong focus on the importance of resuscitation status was expressed as a means to exercise autonomy which was underpinned by the overarching power of the legal system. Second, because agency is constrained in advanced HF, patients' experience of autonomy is incongruent with the dominant individualistic approach and instead, is a relational experience largely based on trust. Third, ACP is shaped by interpersonal relationships, responsibilities, and power differences at the interpersonal and societal levels. Overall, these findings led me to conclude that the process of ACP as described in theory did not align with the understanding of ACP held by participants. The results of this study suggest that patient and family member participants primarily understood ACP as external to treatment decision by focusing on after-death social and financial considerations (such as wills and burial arrangements). Within the healthcare setting, ACP was approached mainly through DNR documentation as clinicians understood resuscitation status to be a key component of ACP. I also found that people experience autonomy as a relational process when participating in ACP, and that social location (specifically relationships, responsibilities and power structures) all shape the experience of autonomy in ACP.

I will give consideration to three main aspects of these study findings. These discussion points include: (1) the relationship between individual autonomy, resuscitation, and the traditional informed consent model in constructing autonomy in ACP, (2) the role of trust and self-trust in autonomy and ACP, and (3) the relationality of ACP and role of social forces that shape this practice. These points were identified for discussion as they underpin many of the situations and perspectives represented in the participants' experiences. I will continue to incorporate the

analytical framework of feminist ethics and relational autonomy, and will also incorporate current related literature from the field to enhance our understanding of the complex phenomenon of treatment decision making and ACP in the context of advanced HF. Finally, I will discuss the limitations of this study and provide a brief conclusion to the chapter.

## 40 Individual Autonomy, Resuscitation and the Informed Consent Model

ACP in its idealized form is understood as an application of the ethical principle of respect for autonomy. Because it is underpinned by the goal of supporting individual autonomy, ACP has been modeled after the practice of informed consent. Therefore, it shares the goal of providing information to people to allow them to express their wishes, thereby supporting voluntary choice and autonomous decision making regarding future healthcare preferences. ACP rests on the assumption that providing information to patients combined with non-interference, or non-coercion by HCP or others, will lead to autonomous decisions, discussion, and documentation of patient preferences (Stoljar, 2011; Advance Care Planning Canada, n.d.). From a legal and policy perspective, these preferences are termed the patients' "previously expressed wishes". Therefore, in theory, by having patients participate in ACP, their SDMs should be able to act on "previously expressed wishes" in order to make healthcare decisions when patients themselves lack the capacity.

ACP is included in the current practice standards for cardiovascular care and is recommended as something that should occur early and often in the HF disease trajectory (Ezekowitz et al., 2017; Allen et al., 2012). However, a key finding in this study was that the majority of participants did not view ACP the way that it is defined in the literature, as a process of "identifying values, reflecting upon the meanings and consequences of serious illness scenarios, defining goals and preferences for future medical treatment and care, and discussing these with family and healthcare providers" (Rietjens et al., 2017 p. e546). Rather, both provider and patient participants associated ACP with death, and accordingly understood ACP as the personal, legal and financial decisions that surround the EOL process. This meant that participants, both patients, family members and HCP, focused specifically on determination of resuscitation status as well as financial and social EOL concerns such as will and burial arrangements. These decisions were

unrelated to their HF management or day to day clinical decision making regarding current or future care. This highlighted the ways people exercise autonomy within both life and death, and demonstrated which aspects of life are understood to be under personal control, such as financial affairs and social arrangements, compared to aspects of life that are under medical control, such as treatment decision making.

The following discussion will examine the various ways that participants understood the process of ACP. Specifically, participants understood ACP primarily as: (1) expressed wishes, (2) resuscitation status documentation, and (3) the practice of informed consent. I will also contextualize these findings with current literature. Overall, by exploring the perspectives and understandings of participants in this study, along with outlining the limits of the informed consent model and some alternative approaches, an overview of the various approaches to constructing and understanding autonomy within the ACP process will be presented.

## 40.1 The Incongruence between “Expressed Wishes” and the Experience of Participants

When considering Stenvoll & Svensson’s (2011) suggestions regarding analyzing for normative absence, we are to ask ourselves “what *should* be in the text that is not there?” (p. 582-83). Considering that the practice of informed consent has been identified as one of the only methods to secure autonomy in the healthcare setting, we *should* see patients and families locating themselves within the process, discussing how they make “voluntary and informed” choices and participate in discussions of consent. In our interviews, the word “consent” was lacking from the participants’ descriptions of their experiences; there was not even a reference to this term or the process that is associated with it from the perspective of the patients or their families. In fact, patients rarely located themselves in the decision making process. There was very little use of “I” when analyzing the patient and family stories. This is an example of when analyzing for an “absence” can be a helpful device (Stenvoll & Svensson, 2011). When patients discussed hospitalizations or treatment decision making, decision making was viewed to be controlled by the healthcare team. This was demonstrated by patients referring to what “they said”, “they did” or “they thought” - the things HCP said or did to communicate plans of care, and the priority that HCP perspectives take over that of patients. Even when explicitly asked about their decisions

and involvement in decision making, patients and family members rarely referred to what “I did” or “I decided”, or even what “I consented to”. The lack of “I” narrative when discussing decision making demonstrates a discourse regarding the large power imbalance that exists between patients and healthcare providers and how this can erase patients’ sense of self and their personal agency.

Diminished personal agency in decision making may lead to discrepant understandings between patients and HCP of what constitutes ACP and what autonomy looks like in the clinical setting. The legalistic perspective of ACP involves identifying patient preferences or their “previously expressed wishes”, which leads practitioners to understand ACP as patients’ ability to identify which type of LST they would consent to, or not consent to, in advance. This is then often reduced to merely a “yes/no” determination of resuscitation status. Schwarze and colleagues described the way clinicians attempt to elicit this type of information about patient preferences in order to recommend treatments by asking SDM, “What would they [the patient] want?” (Schwarze, Campbell, Cunningham, White & Arnold, 2016), and our findings clearly reflect this phenomenon, as HCP framed ACP as the process of determining what patients “want” in advance of a health crisis. This was seen in our data where HCP understood ACP to focus on determining the types of medical interventions patients would “want” (such as surgeries, new medications or deactivation of cardiac devices) if they are unable to speak for themselves.

However, our findings highlight that this construction of ACP as a straightforward process of extracting “wishes and preferences” from patients in advance of deterioration does not resonate with patients’ experiences in the healthcare system, and, therefore, is extremely challenging to truly enact (Truog et al., 2015). Decontextualized “preferences and goals” rarely aligned with the actual goals and values held by patients. Patients rarely (if ever) framed their preferences around specific treatments or interventions they would accept or would not accept; rather, they focused on their personal and social responsibilities, which often revolved around the basic desire to continue to live in order to support their family members. Previous research aligns with this finding by outlining that attempts to extract patient “preferences” tend to encourage a focus on various medical strategies, as opposed to a discussion of the value of different outcomes, such as length and quality of life, which would help patients to plan for themselves and their families

(Schwarze et al., 2016). Consequently, Schwarze and other authors recommend moving away from framing decision making in relation to patient preferences because it encourages the patient and family to reflect on specific treatments, such as life support or comfort care, rather than the goals or outcomes of these treatments.

In the case of HF ACP, it is impossible to be informed of, and understand all the potential treatments that could be offered to a specific patient (Schwarze et al., 2016; Sudore & Fried, 2010; Shapiro, 2015). The results of this study further illuminate that patients and families have to work “in the dark” when considering their understanding of HF and their care preferences. In response to this concern, researchers recommend shifting toward a model that best prepares the SDM to work with HCP to make decisions. However these recommendations still centre on an individualistic model which encourage patients to “communicate their values and needs” in advance (Sudore & Fried, 2010, p. 259), while the findings of this study suggest that this is likely insufficient, as this individualistic model may still be incongruent with the experience of autonomy in chronic illness (Schwarze et al., 2016; Shapiro, 2015).

## 40.2 ACP as Equivalent to DNR Documentation

In this study, participants understood ACP to be strongly connected to resuscitation status, “code status” or DNR documentation. This analysis identified a gap between the way ACP is outlined in the research (as a broad process of identifying values and goals to guide treatment decision making) and the current practice in the context of advanced HF which focuses narrowly on resuscitation measures only (Rietjens et al., 2017). Patients did not view themselves as engaged in the process of healthcare decision making and understood their role to be grateful care recipients who accepted treatment recommendations provided by HCP. Consequently, the only method recognized by patients as an opportunity to exert their autonomy within the healthcare setting was through signing a Do Not Resuscitate (DNR) document. Similarly, HCP understood one of the key aspects of ACP to be the determination of resuscitation status. In Ontario, the only legal ACP documentation includes POAPC documentation and DNR documentation. All other ACP documentation (i.e. workbooks such as Speak Up) is meant to act as a guide for SDMs as opposed to providing strict legal directives that must be followed. Despite recent research which demonstrates that this document-driven conceptualization of ACP is not beneficial and has

limited utility (Shapiro, 2015; Johnson et al., 2018) it is still the main method for conceptualizing this complex practice in the clinical setting, and the presence of ACP documentation is still used as a key outcome measure in interventional studies (Sudore et al., 2017; Johnson et al., 2018; Chan et al., 2018). Therefore, based on this model, it becomes clear why participants often equated ACP to resuscitation documentation, despite the fact that the ACP has been conceptualized as a much broader process.

The understanding of DNR documentation as the main method to exercise autonomy in the healthcare setting is an example of how the patients' role in the consent process is actually constructed as a negative freedom; the right to refuse treatment. This construction sheds light on why patients did not feel they were actively deciding or "consenting" to specific treatment decisions throughout their illness trajectory. O'Neill (2002) explains this phenomenon in great depth; they highlight how autonomous patients are not truly allowed to determine their own treatment, but rather they are only allowed to accept or refuse the treatment that is proposed by professionals (O'Neill, 2002). In O'Neill's (2002) view, the value of patient autonomy is reduced to a right to refuse treatment that is offered, and that this refusal can be quite risky when there are few or no other options for treatment. In response, Mackenzie & Stoljar (2000), along with other feminist philosophers, identify the need for patients to have "a range of significant options" (p. 26) in order to have the conditions to secure autonomy, and this range of options is not often available in the context of advanced life limiting chronic disease. The patient's right of refusal is important because theoretically, it avoids patients being coerced into treatment, however the right to refuse treatment does not secure any distinctive form of autonomy or independence, and the absence of explicit coercion does not equate to the exercise of autonomy (O'Neill, 2002; Dodds, 2000; Sherwin, 2000). Generally, HCP control the healthcare encounter and treatment decision making, and what is broadly referred to as "patient autonomy" masks the fact that "the patient's only role is to say 'yes' or do without treatment" (O'Neill, 2002, p. 25). This exact scenario was demonstrated in this study through patients who found it extremely challenging to refuse biomedical interventions that were offered, and felt that the only viable option was to accept the treatment being recommended because the repercussions of refusal were so immense.



Despite institutional policy requiring code status documentation for admitted inpatients, and the fact that multiple participants in this study had enacted DNR documentation using their own initiative, the existence of a DNR did not contribute to their treatment discussions, nor influence or guide their decisions or care plans in any meaningful way. In a recent article regarding a contentious DNR case for a patient following a complicated heart transplant, hospital staff explained that although the decision to obtain a DNR resides with the patient, a DNR does not actually influence ongoing care and treatment “except for a very specific set of dire medical circumstances, in which a patient may require resuscitation” (Chen, 2019, p. 2). Berger (2003) confirmed that DNR orders are not meant to guide pre-cardiac arrest care, as they do not directly specify care plans or patients’ preferences for treatment except for in states of cardiopulmonary arrest. This highlights an important disconnect in the healthcare system and illustrates the importance (or lack thereof) that is placed on autonomy in clinical practice. Even if patients attempt to control their outcomes using the only method available to them (DNR documentation), this documentation is often unacknowledged and completely unrelated to the clinical care they receive and treatments they are recommended in advance of a cardiac arrest (Berger, 2003). Berger (2003) emphasized this point by outlining how the concept of DNR is inadequate for patients living with chronic disease, yet is emphasized in the clinical setting because it is much more concrete than ACP conversations, which can be broad and more uncertain and therefore challenging and time-consuming for clinicians. This dichotomy seems to encapsulate one of the major concerns with ACP: patients and families have a very narrow range of methods to actually enact autonomy (i.e. only through signing a DNR), but this type of documentation has limitations and “serves poorly to direct broader treatment” because it does not generally influence the healthcare team’s approach, and tends not to override the power of existing pathways, protocols, and guidelines (Berger, 2003, p. 2271; Elliott & Olver, 2008).

This discussion illuminates a major discrepancy between the way decisions are outlined theoretically, legally and in policy, compared to the clinical reality of decision making. Similar to previous research on this topic, patients in this study did not view consent the way it is constructed in policy and education as an important or powerful component of the treatment decision making process (McKneally & Martin, 2000). Participants did understand DNR documentation to hold a certain level of legal power and to be something worth pursuing when

they felt satisfied with their length of life and did not wish to pursue aggressive treatment. This meant that within the current model, the only method for patients to exert their autonomy is through refusal of treatment (O'Neill, 2002) or signing a DNR document. Simultaneously, DNRs were rarely recognized by HCP as an attempt for a patient to exert their autonomy and as potentially relevant to consider beyond merely dictating resuscitation efforts. A notable distinction is that simply having a DNR should not necessarily dictate any specific treatment decision in advance of a cardiac arrest (Berger, 2003), but if patients do complete a DNR document (as patients in our study had), it may be worthwhile for HCP recognize this as one of the only methods available to patients to express their autonomy, and therefore acknowledge the need for further conversation regarding broader treatment plan, goals, and future care decisions.

This focus on resuscitation status only, without acknowledgement of the reasons why one may decide to sign a DNR, is a clear example of how legal frameworks can set the moral minimum for clinical care and demonstrates how the conditions of the law allow for a broad concept such as “expressed wishes” to devolve into a single and limited decision that only considers resuscitation status as opposed to examining broader goals of care. This finding highlights a deeper problem with the way the concepts of autonomy and informed consent are constructed in the literature, in healthcare education and training, and in policies, compared to the way patients and families understand their role in the consent process; as passive recipients accepting recommendations. If the process of ACP is modelled after the process of informed consent, due to their shared goal of empowering and supporting individual autonomy, then it is clear why ACP participation rates remain low patients and families do not have the role in decision making that informed consent suggests that they have.

### 40.3 Constrained Autonomy

A key finding in this study was that agency is constrained in advanced HF, and patient and family experiences did not align with the traditional model of individual autonomy. Participants recognized the impossibility of being completely informed regarding the complexity of HF, and choices were limited (or non-existent) as decision making was guided by clinical guidelines, protocols and candidacy requirements, with little to no room for patient preferences or values to factor into the process. Patients expressing that they have “no choice” but to pursue biomedical

treatment is not limited to this study; indeed, researchers that have examined the experience of patients receiving cardiac devices such as ICD and LVAD have also found very similar results (Fowler et al., 2018; McIlvennan et al., 2014). Aligned with my findings, Fowler et al. (2018) examined patients' experiences of the decision to receive an ICD concluded that patients did not view the process of consenting to receive a cardiac device as their own decision, but rather they understood it as a decision that was made by their physician, or did not acknowledge that getting a cardiac device was considered a decision at all. Participants felt they would do whatever was recommended to them by the healthcare team, and that if a cardiac device was suggested, it was "not something that you could debate" (Fowler et al., 2018, p. 16). Similarly, research regarding the decision making process of patients with advanced HF who were offered an LVAD often recalled that patients felt they "had no choice" in the decision (Dillworth, Dickson, Reyentovich, & Shedlin, 2019, p. 8; Kitko, Hupcey, Birriel, & Alonso, 2016; Ottenberg et al., 2014). Researchers report that patients generally understand medical decision making to be an emotional process of coming to terms with the recommended plan of care, often requiring intensive support from family members or a spiritual community, and that for some, "the desire to live supersedes reflective processing" that should accompany an autonomous decision (McIlvennan et al., 2014, p. 374). Considering that reflective endorsement of authentic desires is a requirement of autonomy (Mackenzie, 2008), it becomes clear how chronically ill patients cannot fulfill the conditions required to exercise individual autonomy.

These findings demonstrate how patients are unable to live up to the ideal of individual autonomy when presented with medical decisions and demonstrates the inconsistencies that result when applying this model to patients who are living with advanced HF, experiencing a high symptom burden, and are being presented with devices that are "necessary" to avoid death. When treatment options are framed as either consent to treatment or certain death (as they were in this study for Han, Peter, and Nathan), as opposed to having a broader discussion of values and goals, the coercive power of death encourages patients to accept various forms of biomedical treatment, despite their goals or values. This binary construction of choosing between life or death limits the opportunities for patients to develop any preferences beyond continuing to live and doing everything possible to stay alive. Having the ability to choose between two options does not necessarily mean that a patient is autonomous, especially when the two options are

narrowly reduced to trying to live or accepting death. This again highlights one of the recurring themes in feminist ethics that acknowledges the importance of having a range of *significant* options in order for an agent to exercise autonomous choice (MacKenzie & Stoljar, 2000; McLeod & Sherwin, 2000).

Although ACP is branded as a means to understand patient desires and support voluntary choice and autonomous decision making, when treatment decisions are consistently framed as a life or death decisions to the patient and family, this limited range of options leads to a continuous cycle of accepting treatment. This often occurs despite the fact that decisions (i.e. to continue life-sustaining measures) may be understood very differently by HCP, who may construct intensive intervention to be futile, and instead of “life or death”, they understand the decision to be “death now versus death later” (Schwarze & Nabozny, 2014, p. 8; Matlock & Mandrola, 2014). This challenge was also seen when considering the term “aggressive treatment”, which meant something positive and productive for patient and caregiver participants in this study, while at the same time was understood mostly as futile treatment to many of the HCP. This lack of common language helps explain why ACP is such a challenging process for people to participate in, and accounts for some of the communication challenges when considering the role of terms like “aggressive” therapy.

Although the participants’ experiences did not reflect an understanding of autonomy being exerted through the practice of informed consent, many participants such as Tracey, Marty, and Brenda, seemed satisfied with the way care decisions were made and managed, which was primarily by the healthcare team, and they were comfortable with the limited role they had in the process, which was exerting autonomy primarily through refusal of treatment if or when they did not agree (which rarely, if ever occurred). Even when participants had strong feelings about their preferences, such as Diane, who did not want to pursue angiography, they generally did not feel as though they should have had more of a role or more decision making authority in their health situations (i.e. Diane would not alter medical appointment schedules to suit her needs). Because of the dominance of biomedicine, the social structure of the healthcare system and the power dynamics at play, patients do not seem to be provided with opportunities to develop autonomy competencies, but they were also not asking for more opportunities to be involved, nor were they

expressing that they were dissatisfied with the level of involvement they currently had. By shifting our understanding of to a relational model of autonomy which focuses on the role of relationships, responsibilities and trust, we may be able to align decision making with the reality of how it experienced for patients, families and HCP who exist within the complex healthcare system.

Another key finding of this study was that patients and families may feel obligated to pursue treatment that is recommended from their healthcare providers due to the social pressures to be good, responsible healthcare recipients and to repay the gratitude they feel. This “debt of gratitude” may override any personal preferences or values the patient may hold regarding their own life goals and treatment trajectory. In a recent *BMJ* editorial, a patient with a history of renal cell carcinoma highlighted how they felt pressure to “do battle and not wave the white flag too soon” when they were diagnosed with a cancer recurrence (Bartlett, 2019, p.1). Bartlett (2019) described how some health professionals automatically assumed they would want treatment and that they felt “there was no room to think otherwise” (p.1). In response to the deep power imbalance, Bartlett ended up writing a letter to the professionals involved in their care, because they were not confident that they could maintain the decision to refuse active treatment and opt for palliative care in a face-to-face meeting with healthcare providers (Bartlett, 2019). This example clearly illustrates the indomitable power of the biomedical machine, and the healthcare providers within it who view the pursuit of treatment as the only reasonable option and who are socialized to think this way as they are trained to cure and “fix” people. The strength of these social forces combined with the interpersonal power dynamics that exist between healthcare providers and patients (Sherwin, 1992) combine to create a situation in which the traditional model of individual autonomy is often not viable and does not resonate with the experience of ACP.

In order to understand how we might align current models of autonomy and decision making with the experiences of participants in order to improve ACP, Sherwin (1996b) suggests employing a process of “feminist reflective equilibrium”: a process that moves between theory and practice to develop ethical proposals that address everyday concerns (p. 191). By going “beyond the general and hypothetical to include practical concerns and observations of everyday

life” (p. 192), Sherwin (1996b) argues that the adequacy of any theoretical proposals should be evaluated by examining what impact they have on current moral problems that are relevant to existing social conditions and circumstances. This process allows us to highlight how existing social arrangements and experiences of autonomy in the healthcare setting may align more closely with relational conceptualizations (Sherwin, 1996b). As Sherwin (1996b) notes, this type of feminist ethical inquiry does not strive to outline a set of eternal moral truths or provide strict normative claims but seeks to highlight specific moral ideals that are relative to current context. This is also important to consider because ACP is not a universal practice, and may not be relevant in many global contexts, however within the context of our current healthcare system which is experiencing increasing technology, growing costs and an aging population, it is highly pertinent to explore this practice in connection to our ability to enact autonomy in an effort to improve outcomes.

## **41 Relational Autonomy: The Tension Between Trust and Constraint**

### **41.1 Interpersonal and Social Trust Substitutes for Information**

A key finding of this study was that decision making was largely based on the trusting relationships developed between patients and family members and their HCP, as well as on establishing trust in the healthcare institutions where they receive care. Even if patients did not choose to trust HCP, or trusted some more than others, due to the severity of their illness and the vulnerability that accompanies chronic disease, they found themselves in positions where they were required to trust the providers caring for them. Because of the dominance of biomedical knowledge and the vulnerability of patients who are ill, in pain, or cognitively impaired, patients and their family members find themselves compelled to trust the healthcare institutions and providers who work within them. Interpersonal and social trust is a fundamental element of relationships and decision making, yet it is excluded from the traditional account of individual autonomy and is, therefore, not currently acknowledged as an element of the decision making or ACP processes (McLeod, 2015; Möllering, 2006). Research by Johnson and colleagues support this understanding, as they similarly found that for physicians, ACP was not about facilitating

patient autonomy but was rather about maximizing trust (Johnson, Butow, Kerridge, & Tattersall, 2018).

The view that autonomy exists only at discrete decision points (i.e. the time of signing a consent form) as opposed to over time through a set of practices serves to bypass the acknowledgement of trust in a number of ways, most significantly by ignoring the fact that interpersonal connections can enable or inhibit an individual's autonomy (McLeod & Sherwin, 2000). Despite this, informed consent can be used as an opportunity to establish interpersonal trust, or trust between a HCP and a patient, through consent discussions (Truog et al., 2015; Waisel, 2019). Truog et al. (2015) outlined how through training, HCP recognized that informed consent was much more than the act of signing a document; rather, the consent process was relational in nature and contained many microethical decisions regarding how clinicians decide to communicate and manage information within the clinical encounter (Truog et al., 2015; Waisel, 2019). Using insights such as this from microethics may allow us to better understand the difference that is typically established between “relational judgements” (small actions that relate to engaging in a trusting professional relationships) and larger “ethical decisions” or actions, such as the act of obtaining informed consent (Truog et al., 2015, p. 11).

Microethics, which has been defined as “an ethic of illness that addresses both the professional provision of treatment and the experience of being ill” (Frank, 1998, p. 37), rejects the notion that clinical behaviour is guided by abstract overarching principles (such as autonomy, justice, etc.) and instead suggests that “ethics is what happens in every interaction between every doctor and every patient” (Komesaroff, 1995, p. 68). I would expand this definition to include interactions among *every type of healthcare provider* and every patient *and family member*. This approach aligns closely with the perspective feminist ethics which locates morality within practices of everyday life and experiences, and within relationships and negotiations of responsibility as opposed to abstract principles (Walker, 2003; Peter & Liaschenko, 2006). As previously argued, this perspective aligns much more closely with the realities of clinical decision making and the ethical issues that surface within the clinical setting (Truog et al., 2015; Komesaroff, 1995; Peter & Liaschenko, 2006). Understanding these microethical nuances may help us avoid over-simplifying the complex process of ACP and acknowledge the fact that

treatment decisions are primarily made within the context of trusting interpersonal relationships with clinicians and family members, as opposed to in isolation and decontextualized from the broader illness trajectory.

Another aspect of trust included institutional or social trust in the healthcare system and the processes that are in place. In order to be motivated to participate in ACP, patients in this study expressed they must trust HCP to either follow the ACP documents or act in their best wishes, yet at the same time patients experienced situations in which they could not fully develop institutional trust with the organization (McLeod, 2002; Rowe & Calnan, 2006). The focus of individual autonomy on the ability of patients to refuse treatments does not account for the types of situations such as this: when patients are ill, vulnerable, unconscious, or have no other treatment options. Comparatively, a requisite aspect of trust is the existence of vulnerability, which is why it is impossible to ignore the role of trust in the lives of people living with advanced chronic disease who are sick and vulnerable (McLeod, 2015). Therefore, the framework of relational autonomy, which focuses on relationships, trust and social location (McLeod & Sherwin, 2000) aligns much more closely with the concerns of participants in this study than the traditional individual model which is concerned with independence and rights.

Overall, the findings of this study demonstrate how the majority of healthcare and treatment decisions leading up until the EOL are controlled by HCP and are made within the framework of trusting relationships between the patient and the HCP within the biomedical model. In theory, the practice of ACP attempts to shift this decision making model to a patient-driven model that is based on personal preferences, values and goals as opposed to biomedical treatment options, guidelines and candidacy. Although noble in intention, it becomes clear why ACP is not achieving its desired results. Patients and HCPs work together over the course of a chronic disease (which may be a many decades-long relationship) and follow specific microethical norms to develop trust throughout this time making decisions together. Yet, the ACP process occurs at the most emotional and vulnerable moments in patients' lives (the months that precede death, characterized by deterioration, hospitalizations, and physical and cognitive decline), and imposes an entirely different model of decision making onto them. In reality, this shift towards a patient-directed model puts an inordinate amount of burden and responsibility onto the patient, or in



many cases, the SDM to make decisions on behalf of their loved one and their “expressed wishes,” even though they may have never done this previously. If instead of attempting to implement a new model of decision making at this vulnerable time, we capitalized on the existing relational skills that are developed within the daily microethical encounters, HCP would be able to move away from the narrative of individual autonomy and instead develop a relational model that better serves patients and families and is based on existing interpersonal relationships, responsibilities, and trust. If ACP continues to be framed as attending to large ethical decisions related to resuscitation, EOL care and resource allocation, we fail to capture the nature of daily decision making and continue to see a lack of engagement in ACP.

## 41.2 The Role of Self-Trust in Relational Autonomy

As noted by Joseph-Williams, Elwyn & Edwards (2014), a patients’ capacity to participate in decision making is linked to their perceived ability to influence the decision making encounter. The authors suggest that patients need to be supported to feel capable of acquiring and understanding biomedical knowledge and taught to value their personal contributions to the decision making process (Joseph-Williams et al., 2014). Based on the results of this study which found that patients often take the role of being passive recipients of care and have limited autonomy in treatment decision making, enhancing self-trust could be a way to increase patient capacity and is therefore relevant to explore further in this discussion.

Relational autonomy proposes that self-referring attitudes such as self-trust, self-respect and self-esteem are developed through interpersonal relations and recognition and are necessary for the exercise of autonomy (McLeod & Sherwin, 2000). According to Govier, self-trust, or the ability to regard oneself as the legitimate source of authority, is a necessary condition for personal autonomy (Govier, 1993; Mackenzie, 2008). Trusting oneself involves having a positive sense of one’s motivations and a belief in one’s capacity to not only make appropriate choices given personal values and desires, but to act on these decisions and trust the judgements that underlie these decisions (Govier, 1993; McLeod & Sherwin, 2000). The skill of self-trust is especially relevant to the exercise of autonomy because it allows for reflective endorsement of the motivations and values that guide self-directed action and allow for normative authority to develop within a person (Mackenzie, 2008). Further, self-trust allows people to move from being

passive recipients of negative freedom to active agents in the self-direction process who can evaluate and act upon personal values and motivations (McLeod & Sherwin, 2000).

Previous research has outlined how physicians effectively “control” ACP, as they possess both the expert knowledge about a patient’s diagnosis, prognosis and treatment options as well as professional power relating to timing, structure and content of ACP discussions (Johnson et al., 2016). Additionally, the realities of the time and resource-constrained healthcare system do not frequently allow for opportunities to develop autonomy capacities within the health and illness decision making aspect of life. These conditions all interfere with the development of self-trust because once internalized, oppressive norms block the agents’ abilities to critically evaluate motivations, values and belief. Stoljar (2011) calls this phenomenon the “blocking of an agent’s normative competence” (p. 379). This results in patients who are lacking self-trust and the ability to make and act upon decisions that are appropriate to them within the healthcare setting, or as Joseph-Williams et al. (2014) express, patients who undervalue their own expertise and its relevance to the clinical encounter.

Self-trust is an imperative component of relational autonomy and should be acknowledged within the healthcare setting, but unfortunately, opportunities to develop self-trust within routine healthcare processes are not available to most patients. For example, in my analysis of patients with HF attending specialized HF clinics, the HCP provides recommendations for treatments and the patients usually accept these recommendations. This transaction does not usually involve a robust discussion of options for treatment, risks and benefits of various therapies, exploration of the patients’ preferences or values related to the treatment, or the opportunity for patients to make a choice for themselves. This limited involvement in decision making is highlighted explicitly in the existing literature that examines the experience of patients receiving ICD therapy, and the limitations of the informed consent process (Strachan et al., 2011). Therefore, the self-trust that may be developed by making appropriate health decisions throughout the course of an illness is limited. In our current model, patients attribute positive results to the decisions and actions of the HCP and do not view transactions as shared decision making processes that are based on personal values and preferences (Fowler et al., 2018). Many people do not have prior experience making complex (or even simple) medical decisions and have not

developed this competency of self-trust within the medical or healthcare realm of their lives, despite the fact that they may have quite well-developed autonomy capacities in other areas. Coupled with the lack of exposure to death and dying, patients may rarely have adequate self-trust to be able to fully exercise self-direction in the ACP process and in the EOL setting.

This is problematic because the current process of ACP relies heavily on the idea that all patients possess adequate autonomy competencies and have sufficient experience making healthcare decisions, and therefore have developed preferences regarding what kind of treatment and care they may want. This process also assumes patients are able to fully access these autonomy competencies when making challenging decisions regarding future care as well as decisions regarding death and dying. As Johnson and colleagues (2016) note, the notion that ACP is concerned primarily with the patient's right to self-determination through control over treatment choices at the EOL may actually misrepresent the way that these decisions are made and conflict with the deeper needs of patients, who experience ACP as a relational, emotional, and social process. An appropriate relational approach to ACP would attend not just to healthcare choices but also to the ways in which participating in this process can contribute to and support the development of self-trust within patients.

## 42 ACP as a Relational Experience

The results of this study demonstrate that health and illness decision making is based not only on the self, but also on the numerous relationships and responsibilities one may hold at any given time, and that ACP is not an individualized process but rather a relational experience.

Relationships were especially important in this study, specifically the role that relationships played in supporting autonomy. These relationships were examined using a relational ontology, which explored participants' various accounts "in terms of their relationships to the people around them and their relationships to the broader social, structural and cultural contexts within which they live" (Mauthner & Doucet, 1998 p. 125). Van Heijst (2009) suggests that because respect for autonomy is a central value in current biomedical ethics and healthcare delivery, HCPs must attend to the patient's conception of "the good" (p. 201), which should expand beyond merely curing disease to understand the good that can also be found in both sickness and death. However, as opposed to avoiding paternalism and encouraging autonomous decision

making, which are the traditional suggestions to achieve this goal in autonomy-focused literature, van Heijst (2009) argues that we need new ways of determining what benefits those who are chronically ill and vulnerable, and these approaches should be grounded in interpretive and relational methodologies. Taking into account the findings of this study, I suggest that using relational autonomy as a framework for re-designing ACP and guiding decision making in the healthcare realm may be one way to access, account for, and respond to the patient's (and family's) conception of the good. The following discussion will examine two key ways that relationality factors into the ACP process: the substitute decision making process and the influence of social forces.

## 42.1 Inherent Relationality of Substitute Decision Making

Despite the individualistic and rational way ACP has been outlined in the literature, the results of this study showed that there was no formal process for patients to engage in current or future decision making regarding their care, especially when throughout the illness trajectory, care decisions tend to be dictated by the care team and approached as a family unit working from the basis of shared goals. By focusing only on what the patient wants, or their "previously expressed wishes" we obscure the fact that people live within an interconnected web of relationships (McLeod & Sherwin, 2000; Ho, 2008) and there often may be no significant difference between what the patient wants and what the SDM would want for themselves. Trying to distinguish between what is in the patients' best interest without acknowledging that the patient and SDM often share values and goals, and what is best for one is determined in relation to the impact on the other illuminates one of the shortcomings of current models of ACP (Ho, 2008). As Donchin (2000) notes, "what we want for ourselves may not enhance our autonomy if it can be attained only by dodging responsibilities towards others who depend on us" (p. 246). Therefore, attempting to isolate individual desires from their relationships does not align with the way people make decisions in reality, which involves a balancing of interests and a sharing of goals. This point has also been highlighted in previous studies such as Strachan et al. (2009), where researchers found that patients with advanced HF were primarily concerned with burdening their families with "increasing physical or emotional needs" (p. 637). This type of relationality is not accounted for within traditional ACP conceptualizations, nor in interventions which focus on

extracting the authentic and rational desires of an isolated individual, and, therefore, traditional conceptualizations of ACP may not be highly useful to patients and their SDMs.

In addition, traditional conceptualizations of ACP often gloss over an extremely important point: the process is entirely dependent on having an SDM that is open and willing to discuss the intimate details of EOL care and face the death of someone who is likely one of the people they love most in the world. This takes a combination of a deep understanding of the illness, an ability to manage the most challenging emotions, and the confidence to discuss death, which is rarely addressed in society. The discussion involves the horror of having to imagine the demise of the person one loves and removing all emotion in an attempt to have a rational conversation about care preferences and logistics. From this perspective, it is clear why this process is unappealing and may be something patients and families are unable to do, even if the patient is entirely “ready to go”, as some of the patients in this study expressed. The role of the SDM, who is often the patient’s primary caregiver and advocate throughout the course of a long illness, and the emotionality of this role is rarely acknowledged in most of the ACP literature and interventions, aside from the requirement that the SDM become aware of the preferences of the patient, and make objective decisions on their behalf.

To draw a parallel, the American Medical Association’s [AMA] “Code of Medical Ethics,” (AMA, Opinion 1.2.1 and 8.19) states that “physicians generally should not treat themselves or members of their immediate families” due to concerns about objectivity, patient autonomy, and informed consent. Similarly, both the Canadian Medical Association [CMA] and College of Nurses of Ontario [CNO] recommend that providers should only care for family members or close friends in emergency situations where there are no other care providers available (CNO, 2006; CMA, n.d.). However, through the process of substitute decision making, we routinely ask family members to “objectively” make medical decisions related to resuscitation, interventions, and EOL care without acknowledgement of the incredibly challenging nature of these decisions. Not only this, but we are concerned with SDM influence during periods of incapacity (and focus on ensuring the SDM only considers the patient’s best interest and not their own), yet we fail to adequately acknowledge their supportive role in decision making throughout the entirety of the illness trajectory. Although ethicists and clinicians expect SDMs to use substituted judgment or

patients' best interests when making decisions, research also indicates that SDM may rely on other factors such as the mutual interests of themselves and the patient (Vig, Taylor, Starks, Hopley & Fryer-Edwards, 2006). This demonstrates another way that the model of individual autonomy fails to account for interpersonal relationships and their influence. In the end, we do not support the development of decision making competencies or capacities in SDMs in advance of requiring them to make complex EOL decisions (Shapiro, 2015). Overall, as Fins et al. (2005) note, the process of delegating autonomy to a SDM is morally complex, and substituted decision making often requires SDM to take on an “interpretative burden” (p. 55). in order make “nuanced and contextually informed moral judgements” on behalf of the patient.

Not only this, but when family members are asked to make decisions on behalf of their loved ones in the role of SDM, we fail to acknowledge that through this act, families are required to make moral judgements about the value of their loved one’s life, which includes judgements regarding the value of their personal relationships (Elliott & Olver, 2008). In this arrangement, choosing to forgo life-sustaining therapies (such as resuscitation) is constructed as choosing to let a family member die (Elliott & Olver, 2008). This leads to two equally unappealing options for SDMs – either they decide that the patient is not valuable enough to save, or that the family does not care enough to save them (Elliott & Olver, 2008), and then they must live with the negative moral and social repercussions of either decision. In this model, the formal responsibility for the decision is transferred to patients and families, and the unacknowledged consequence of this is that patients and families then live with the responsibility for stopping treatment, or worse – constructing this choice as “killing” their family member. The consequences for living with this type of responsibility are relatively unexplored, however, it has been reported that family members who are required to make substitute decisions experience negative emotional effects, most commonly stress, guilt over the decisions they made, and doubt regarding whether they had made the right decisions, and these feelings often last months to years (Wendler & Rid, 2011). Overall, requiring SDMs to provide an “objective” decision based solely on preferences of their loved one and having them take responsibility for this decision does not reflect the way decisions are made in relationships or in the clinical setting, and, therefore, it again becomes clear why patients and families may not be able to engage in this process.

## 42.2 Power Structures Override Autonomy

A key finding in this study was that the current construction of ACP reflects societal power structures, specifically related to the dominance of biomedicine, which produces rigid clinical guidelines and protocols that perpetuate avoidance and denial of the possibility of death. In addition, neoliberal ideologies of independence, self-management and personal responsibility downplay consequences for health outcomes to patients, while also rejecting the role of aging, decline and dependence in the need for and utilization of healthcare services. These two structures will be each explored in depth.

### 42.2.1 The Tyranny of Evidence-Based Practice and the Medicalization of Death

As outlined in the introduction to the results, the social context of the biomedical institutions in this study shaped the experiences of the participants and the treatment options available to them, demonstrating the relational nature of autonomy that is influenced by social structures and opportunities (McLeod & Sherwin, 2000; Sherwin, 1989a). As a note, participants in other parts of the province or country with different access to specialized centres, or without the ability to travel, may have had different experiences or may have made different choices (i.e. to continue receiving care at their local institution). The ability to self-govern and make these types of choices was both defined and pursued within this social context of the Ontario healthcare system, and the analysis revealed the role that institutional and societal cultures can play in understanding the HF trajectory and the complex phenomenon of ACP within the Canadian context (MacLeod & Sherwin, 2000).

Although HCPs in this study expressed that they would like patients to express their wishes about medical treatment in order to follow hospital policy and broader legislation, there was no institutional framework that was routinely used to guide the process of translating patients' personal goals and wishes into treatment decisions, and there was an overall lack of support for patients, families and HCP to enact ACP the way it is defined in the literature. As highlighted in the findings, enacting ACP by attempting to tailor treatment recommendations to patient preferences (i.e. limiting recommendations for intensive treatment or providing intravenous

diuresis at home) meant that providers could be seen as negligent (or worse) for delivering care outside of what is considered to be standard best practice. Maintaining the standard of care in HF management often meant complying with clinical guidelines that primarily recommend intensive treatment, invasive therapies, or aggressive medical management and follow-up without consideration of age, quality of life, or patient preferences.

This underscores one of the challenges of ACP that goes beyond time and training – that even those who make the time and have the training to provide personalized care, find that the system is not designed to support this type of personal tailoring of treatment plans, as providers felt obligated to follow clinical guidelines and algorithms which dictated treatment choices. These clinical guidelines and protocols are “evidence-based” which is commonly assumed to be quantitative studies employing randomized controlled trial design; the “gold standard” of research evidence (Rycroft-Malone et al., 2004). Guidelines are often developed with a strong focus on treatments such as medications, devices, and procedures, and outcomes that can be measured as quantitative improvements in morbidity, mortality and cost. As noted by Rycroft-Malone et al. (2004), the development of this hierarchy of evidence has allowed for the relative neglect of other forms of evidence in the delivery of health care and, therefore, the “interaction of research evidence with contextual, individual practitioner and patient variables has been disregarded” (p. 83).

An example of this tension between research and practice was also highlighted when considering the repercussions of a lack of age cut-offs in clinical cardiovascular care guidelines. This was especially relevant to device implantation guidelines, which can lead to elderly patients having a device recommended merely because that is what the guidelines dictate, without a robust discussion of future goals. This concern has also been highlighted in other recent literature, to demonstrate how the priorities of medical device companies (who often support the funding of these studies) and the powerful discourse of biomedical research intersect to influence guideline development, and the repercussions this can have on patient care (Fowler et al., 2018; Munro, 2020). The strict adherence to clinical guidelines and candidacy requirements in cardiovascular care leads to a strong power imbalance between HCP, who are supported by “gold standard” evidence and clinical guidelines, and the patient, who has only personal experience, which does not even have a place within the “hierarchy of evidence” (Petrisor & Bhandari, 2007).



Strict adherence to clinical guidelines also inherently promotes the avoidance of death.

Acknowledgement of the terminal nature of HF is rare, and focus remains on treatments and therapies while reference to practices such as ACP or referrals to palliative care are limited (Ezekowitz et al., 2017; Kavalieratos et al., 2014). In clinical trials designed to test therapies for HF patients, morbidity and mortality are negative outcomes commonly used for measurement purposes, and as discussed in the results, referring a patient to palliative care signals to other HCP that the team has “given up”. This extreme focus on the pursuit of biomedical treatment leads to limited opportunities to discuss the reality of HF and the eventuality of death.

Additionally, preparing and planning for death is something that most individuals in Westernized societies have little exposure to. Death has shifted from taking place in the home to taking place in the hospital, and with the advent of many curative treatments and procedures, fewer and fewer Canadians die at a young age. Overall, high income countries have less exposure to the death and dying process and, therefore, lack opportunities to develop values, beliefs, and knowledge regarding the processes of illness and death. This lack of exposure leads to limited opportunities for people to develop the important self-referring attitudes, such as self-trust, that allow them to make self-directed decisions in a certain domain of life, such as EOL care. Therefore, people have limited information, understanding, and endorsement of personal values and beliefs that contribute to the social process of dying, leading to underdeveloped self-referring attitudes in this domain, which impedes upon the ability to act autonomously. Nevertheless, the current process of ACP expects individuals to make rational, informed and self-directed decisions when trying to plan for their own EOL experience and fails to acknowledge the dominant power of biomedicine that seeks to prolong life and avoid death at all costs.

#### **42.2.2 Advance Care Planning: A One-Dimensional Neoliberal Solution?**

As mentioned earlier in this thesis, neoliberalism emphasizes individualism, self-care, and self-sufficiency and utilizes the language of autonomy, empowerment, and control as a way to download responsibility for decision making onto patients and families (Petersen, 1997; Coburn, 2000). Neoliberal rationality emphasizes autonomy and the capacity to care for oneself and calls upon individuals to pursue self-governance “through processes of endless self-examination, self-care and self-improvement” (Petersen, p. 195, 1997). This downloading of responsibility onto the

individual is a hallmark of neoliberalism, and illuminates the neoliberal message that patients must demonstrate that they are good and responsible citizens, and that they will be held responsible for the success of their medical treatment, when in reality, they have very limited control over their outcomes.

Another central process of the neoliberal agenda is cutting costs to improve efficiency (McGregor, 2001), which was tangible in the context of this study whereby despite being located within a high-income country, the Ontario healthcare system is strained. One of the recruitment sites for this study was running at a multi-million dollar deficit and services were being cut across the institution and across the province. It is not a coincidence that renewed interest in ACP has been demonstrated in recent years as healthcare costs continue to exponentially grow, and there has been a specific focus on the spending that occurs for patients in the last month of life (Tanuseputro et al., 2015). This has led to further research and discussion regarding the cost of providing intensive therapies as people age and approach death, which has produced challenging social questions regarding medical futility, resource allocation, and ethical decision making (Fowler & Hammer, 2013). The power of neoliberal discourse stems from its ability to “provide social and political questions with technical and non-ideological answers” (Defossez, 2016, p. 78). Specifically, health practices such as ACP can be important tools used in neoliberal society to implicate the patient in the failings of the healthcare system or larger government, which in this case is the failing to attend to pressing social issues such as growing healthcare expenditures and the care of the aging population. This combination of biomedical dominance in a neoliberal landscape extends to assigning moral value to people in society who enact neoliberal values, which was illustrated in patients who were candidates for advanced therapies seeming to have a higher moral value than patients who were not. The amount of time and resources put towards people who are pursuing biomedical treatment combined with the structure of the system which inherently favours those who continue to accept treatment and rewards physicians based on quantities of devices inserted and procedures completed, supports the overarching push to continue to provide and accept interventions. This is a stark contrast when compared to the limited options available for those who do not or cannot receive further intensive biomedical treatment. These patients may benefit from palliative care or home care. However, these systems

are under-resourced and restricted due to limited funding and the hegemony of curative acute biomedical care.

O'Neill (2002) explains that the appeal of autonomy in the healthcare setting is that it gives the illusion that people can challenge the professional authority of healthcare providers, while in reality the existing power structures allow biomedical authority and neoliberal discourse to remain largely intact. Johnson et al. (2018) found physicians understood ACP to be something “the system wants us to do to make the system work better [...] under the guise of respecting patients’ wishes” (p. 572). While the prospect of giving patients more agency in the context of decisions related to EOL care seems admirable, some scholars as well as participants in this study are wary of the motivations for, and the consequences of practices such as ACP (Defossez, 2016; Johnson et al., 2018). Defossez (2016) argues that a sole focus on the technical means of death and the logistics of documentation eclipses possible considerations of the ethical aspects of EOL, and frames decisions as matters of “technological as opposed to moral agency” (p. 77).

This interpretation may help explain why ACP has become such an important healthcare practice that has achieved federal attention in the form of a national task force (Advance Care Planning Canada, n.d.). As opposed to HCPs or governments having to make a decision regarding the value of life at various ages or stages of health, the practice of ACP allows governments to enact social control by emphasizing self-management; this also serves as to communicate the social value of the elderly and sick who are using a significant amount of healthcare dollars, yet frames the process as a means to enhance personal autonomy and involvement in decision making (Robins-Browne, Palmer, & Komesaroff, 2014). Using this model, in which the goal of ACP is to benefit the system financially “under the guise” of supporting patient autonomy (Johnson et al., 2018, p. 572), ACP will continue to underperform due to the unrealistic expectations of this practice. However, it remains imperative to retain some form of ACP within the current context of our healthcare system, in order to continue to attempt to align patients’ goals with the healthcare and treatments they receive, and overall to improve outcomes for patients, family members, providers, and the system as a whole. Re-designing ACP interventions using a relational model of autonomy may be one method to improve the experience of ACP for patients and families. In alignment with Johnson, Kerridge, Butow & Tattersall (2017), I agree that

meaningful improvements in EOL care will likely not result from the institutionalisation of ACP, but rather must attend to broader social conditions and forces that created these social problems.

## Chapter 10

### Conclusion, Implications and Future Directions

In this concluding chapter, I first present a summary of the key ideas from this study, followed by a discussion of the limitations of this work. I then outline some of the contributions of this research, including empirical, theoretical and methodological considerations. Next, I move on to explore the implications of the study findings for nursing practice, education in the health sciences, and health policy. In doing so, I reflect on how the understandings developed by this work might ultimately help patients, family members, and HCP in the context of advanced HF and beyond. I conclude this chapter by proposing directions for future research and suggestions for further theoretical and empirical work that may be conducted on this topic.

#### 43 Summary of Key Ideas

Despite the continual development and innovation of medical therapies, medications and devices to improve the symptom burden and health outcomes for patients with advanced HF, the mortality rate of HF continues to be worse than many common cancers (Shah et al., 2017; Ko et al., 2008). Due to societal norms that idealize biomedical treatment and stigmatize decline, dependence and death, the majority of HF patients receive intensive and invasive therapies well into the final months of life, despite evidence that many would prefer to receive supportive care and die in the community (Warraich, Hernandez, & Allen, 2017; Unroe et al., 2011; Kaul et al., 2011; Formiga et al., 2004). ACP has been identified and promoted as a key method of promoting patient autonomy, improving patient and caregiver outcomes, and lowering healthcare costs at the EOL by aligning biomedical treatment with patient preferences (Brinkman-Stoppelenburg, Rietjens & Van der Heide, 2014; Kernick et al., 2018; Dixon, Matosevic & Knapp, 2015). However, despite over 30 years of research, intervention development and public awareness campaigns, participation and engagement in the ACP process has remained low in both HF specifically as well as the general public (Butler et al., 2015). Even among recently hospitalized elderly patients, who are known to be at increased risk of rehospitalization and death, less than 5% had ACP documentation available to the healthcare team (Knight et al., 2020). Therefore, the goal of this research was to better understand the practice of ACP within

this complex population by focusing specifically on exploring the experience of autonomy and the way it is constructed and expressed by patients, caregivers and HCP. Overall, this study provided a relational examination the experience of autonomy in advanced HF and how it relates to participation and engagement in the ACP process.

As discussed in the literature review, many researchers have previously attempted to implement ACP in the HF population, and some studies have also explored the associated barriers and facilitators to this practice (Briggs et al., 2004; Schellinger et al., 2011; Kirchhoff et al., 2010; Kirchhoff et al., 2012; Sadeghi et al., 2016; Metzger et al., 2016; El-Jawahri et al., 2016; Anzai et al., 2019; Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2014; Greutmann et al., 2013; You et al., 2017). While much is known about how barriers, such as time, training, and the discomfort discussing death, influence people's willingness to participate in ACP (Ahluwalia et al., 2012; Ahluwalia et al., 2013; Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2014; Chandar et al., 2016; Gigon et al., 2015; Zwakman et al., 2018), less is known about how autonomy is understood, experienced and expressed through this process (Dove et al., 2017). Few studies have examined the experience of autonomy in ACP in relation to wider discourses such as the biomedical model of disease management, the medicalization of the decision making in advanced illness, and the relationality of the process of ACP (Robins-Browne et al., 2017; Lin et al., 2018). By offering new ways of understanding autonomy through a relational exploration of ACP, this study challenged the current literature that often portrays ACP as a simple process of discussion and documentation that is grounded in individualized autonomy. By examining the various perspectives of those involved in this phenomenon, I reconsidered how patients understand and enact autonomy within the constraints of the healthcare system, and the role of social location in this process. Drawing upon feminist ethics and feminist conceptualizations of relational autonomy as an alternative to the traditional individualized approach, the first objective of this study was to explore the ways people understand and approach autonomy through the ACP process. The second purpose was to characterize the ways autonomy is experienced and expressed in the context of advanced HF. Finally, the third goal was to outline how social location mediates the experience of autonomy in the context of ACP.

The overall results suggest that there are diverse ways of understanding the process of ACP in the context of advanced HF, yet simultaneously, there is little connection between the traditional

individual model of autonomy and the realities of decision making experienced by participants. The tensions generated by the conflict between the legal discourse of informed consent and the clinical realities of protocolized decision making in the context of advanced chronic disease led to limited opportunities for participants to develop and express autonomy within the traditional framework. Ultimately, autonomy was governed by wider discourses that prioritize the pursuit of biomedical treatment and the primacy of evidence-based protocols and guidelines over the development of autonomy.

The results of the data analysis suggest that the experience of autonomy in ACP was not aligned with the traditional individualistic approach, but rather was developed through the complex interrelation of interpersonal relationships, opportunities for decision making, and broad social forces that shape the narratives of illness and death. Overall, there were three key findings that resulted from this exploration of ACP with the HF population. First, ACP was a complex social process, often positioned outside of standard treatment decision making within the biomedical model. Documentation of DNR status, underpinned by the overarching power of the legal system was the only means for patients to exercise autonomy. Second, the agency of patients was constrained in advanced HF due to the limited understanding of complex information, limited treatment options that decrease opportunities for decision making, and the fear of death which favours decisions to extend survival time by accepting treatment. Because of these contextual influences, patients' experience of autonomy was incongruent with the dominant individualistic approach and instead, was a relational experience. Finally, the findings indicate that autonomy in ACP was shaped heavily by interpersonal relationships and responsibilities and was influenced by interpersonal and social power dynamics as well as broad social forces related to neoliberalism, ageism and medicalization.

## 44 Limitations of the Study

This study was conducted in one large, specialized cardiac care centre, and one smaller, academic urban hospital, both within the publicly funded Canadian healthcare system. Because of the location and proximity to specialized care centres, the possibilities for patients to obtain a

variety of treatment options were potentially greater than in a smaller institution in a rural area, and much greater than the options available in a lower-income country, which may limit the transferability of results to other countries or settings. Healthcare institutions with limited budgets may not be able to offer patients the types of therapies that characterized the HF trajectories in this study, such as access to cardiac transplantation, access to new and expensive technologies and therapies (i.e. MitraClip®, various implantable cardiac devices), and access to specialized interdisciplinary HF care teams.

An important limitation of this study was that the participants did not represent a wider range of social locations, despite efforts to recruit a broader sample. The sample was heterogeneous in terms of demographic criteria such as gender, ethnicity, pathophysiological basis and experience of HF, as well as HF treatment trajectories. However, overall, participants had supportive social networks, were relatively health literate and were able to advocate for themselves in English. With the exception of Peter (Case Three), who described the personal consequences of having advanced HF by having to move homes in order to be closer to family and to treatments, participants appeared to be relatively stable socially and financially. Moreover, certain participants seemed to have relatively high socio-economic status based on field observations during interviews which took place in the home environment.

The range of HCPs represented in this study sample could be considered both a strength and a limitation. The heterogeneity of the sample supported the synthesis of multiple perspectives, an exploration of the ways different professionals approach and understand the ACP process. This heterogeneity also encouraged an examination of relational tensions that exist among providers and allowed for exploration of the conflicting viewpoints and various priorities held by providers, patients and families. However, the diversity of the sample also meant that I was unable to provide a focused understanding of the experience of any one specific provider type. Because this study recruited patients from the outpatient clinic setting, the nurses that patients primarily interacted with were nurse practitioners. Therefore, the perspective of registered nurses, who provide direct care to HF patients and their families during inpatient and intensive care admissions, was absent. Registered nurses may hold a different perspective on the relationality of the ACP experience, incorporating their perspectives would be valuable in future work.



## 45 Contributions to Knowledge: Empirical, Theoretical and Methodological

### 45.1 Empirical Contributions

Although some previous research, both empirical and theoretical, on relational autonomy and medical decision making has been conducted, (Bell, 2014; Bell & Balneaves, 2015; Ho, 2008; Sherwin & Winsby, 2011; Dove et al., 2017), and relational autonomy has been discussed as a potential conceptual framework for ACP (Robinson, 2011; Siddiqui, 2016; Lin et al., 2018; Thoresen & Lillemoen 2016; Gómez-Vírseda et al., 2019), there have been few empirical studies that have employed relational autonomy as a framework to understand the complex phenomenon of ACP. More recently, studies have examined the concept of “relational knowing” in the context of ACP, (Robins-Browne et al., 2017) yet there have been few studies that have used the practice of ACP as a means to examine the nature and experience of autonomy within the healthcare setting in the context of advanced chronic disease (Killackey et al., 2019a; Killackey et al., 2019b). Therefore, this study was one of the first in the health sciences to employ a relational understanding of autonomy to examine how people with advanced HF approach ACP and exert their autonomy through this process. The findings of this study suggest that relational autonomy is a more suitable framework for the provision of ACP than the traditional individualistic model that is used currently.

There has also been previous conceptual work using relational autonomy that has problematized the process of informed consent and the ability to be autonomous in the healthcare setting (Stoljar, 2011; McLeod & Sherwin, 2000; Mackenzie & Stoljar, 2000; Sherwin, 1992). However, this was study also one of the first to employ empirical methods and collect data from diverse sources and perspectives to understand the phenomenon of autonomy in ACP in an innovative way, within the framework of feminist ethics. By moving beyond the existing legal, ethical and biomedical norms that narrowly conceptualize ACP from an individualistic perspective, this study contributed new knowledge of the broader social conditions that shape the ACP process and the discrepancies that exist among theory, legalities and policies of ACP and the daily experience of people living with advanced HF.

In contrast to the broad and holistic scope of this study, which moved between the interpersonal, institutional and social levels of interaction, the current literature on this topic tends to accentuate individual behaviour change. Due to this trend, many studies are framed by underlying assumptions of neoliberal individualism: that patients are independent, rational actors who have specific preferences that can be extracted and documented. This study did not assume this traditional model of autonomy, and also did not ignore the power relations inherent in the ACP process, which allowed for the generation of novel findings. Specifically, (1) DNR documentation is the only method available to patients to exert their autonomy, yet it does not influence treatment decision making prior to resuscitation; (2) ACP is closely related to trust, yet patients may not inherently trust ACP documentation; and (3) healthcare providers, although knowledgeable and relatively powerful, can also find themselves caught within the clinical inertia of the protocol- and guideline-driven biomedical machine. These findings have not been reported in previous examinations of the process of ACP and may help identify root causes for low ACP participation rates. As discussed in the literature review, current literature on this issue occasionally suggests patients, family members and HCP are unwilling and uncomfortable when addressing and discussing death, which leads to challenges conducting ACP. This perspective narrowly frames people as fully informed, voluntary agents who are able to choose to either participate or not participate in ACP, however, this was not the case for participants in this study whose experiences were heavily shaped by the range of options and opportunities available to them within the existing social structures and power relations.

By highlighting the broader context that informs ACP, as well as the social forces, power dynamics, and relationships that guide this process, this study problematizes the individualized view of autonomy in ACP and in healthcare decision making as a whole. This study described the complexity of people who navigate living with advanced HF within their network of relationships, responsibilities, and opportunities, and the way social location shapes the experience and expression of autonomy. This experience was conceptually outlined in this study by mapping the various ways that agency is constrained in advanced chronic disease, and highlighting the relational aspects of the ACP process, which is a new and important contribution to the field. Additionally, although this area of research is developing, few studies have examined the experience of autonomy through the process of ACP for patients with advanced HF

specifically. Therefore, this study contributes to the growing body of literature in the HF field and supports the development of further research which seeks to understand and advance ACP in this complex population.

## 45.2 Theoretical Contributions

Overall, this study contributes to the development of relational autonomy theory in a number of ways. First, by using ACP as an observable enactment of autonomy within the healthcare setting, I was able to demonstrate the utility of relational approaches to autonomy when considering the types of decision making that occur in advanced chronic disease. Second, by examining the various relational elements of the ACP process, I was able to step outside of the dominant narrative of traditional individualism and identify some weaknesses of the current approach to promoting autonomy in healthcare settings, and consequently, some strengths of the relational model. Specifically, I identified the way agency is constrained in advanced disease which limits patients' ability to engage in ACP, and highlighted the influence of power relations, both interpersonal and systemic, that shape this process. Finally, by using a diverse sample I was able to demonstrate the way that relational conceptions of autonomy are worthy of further exploration for a variety of patients and how this framework is relevant to patients of various genders living within different social networks and at different points of the chronic disease trajectory.

As mentioned earlier in this thesis, feminist ethical theory brings attention to the social location of moral agents in general with an explicit focus on vulnerable and oppressed groups (Sherwin, 1992; McLeod, 2000; MacKenzie & Stoljar, 2000), but, as opposed to mainstream feminist theory, does not necessarily prioritize gender over other social factors (Dodds, 2000). In this study, the dominance of biomedicine and the individualistic model it adopts was found to be a source of constraint for all patients and families. Although much of the early literature on feminist ethics focused on female health related concerns (Sherwin, 1992; Mackenzie & Stoljar, 2000), more recently the framework of relational autonomy specifically has been used in a number of other areas including as a means to explore the autonomy of nurses (Macdonald, 2002), the family's role in medical decision making (Ho, 2008), the autonomy of nursing home residents (Sherwin & Winsby, 2011), the decision making of cancer patients in relation to clinical trials (Bell & Balneaves, 2015) and the autonomy of people who use drugs (Lago, Bogus

& Peter, 2018). These studies, along with the results of this research, reveal the broad applicability of the framework of feminist ethics and relational autonomy and demonstrates how this framework may expand to consider issues beyond the limits of female health concerns.

## 45.3 Methodological Contributions

There are few studies that have combined a case study approach with feminist ethics, and even fewer that have used the process of case construction as a specific method of examining and analyzing the tenets of relational approaches to autonomy. This is the first study to use a feminist ethics-guided multiple case study approach to examine the relational nature of autonomy through the process of ACP. The method of case construction allowed for the analysis of multiple perspectives, and an exploration of the tensions that exist within the multiple roles and responsibilities of people living with and working with advanced HF (Baxter & Jack, 2008; Meyer, 2001; Dooley, 2002). By incorporating a variety of methods of data collection, this study illustrates the utility of case study methodology in the study of multifaceted practices such as ACP (Carolan et al., 2015; Meyer, 2001; Marshall & Rossman, 2010) and highlights the potential transferability of this approach to the study of other complicated clinical problems across various populations. Using numerous empirical data sources from a diverse sample of patients, caregivers, HCP and documentation led to a better understanding of the social dynamics of ACP and autonomy more broadly. An additional strength of the combination of this methodological and theoretical approach was that the complexity of the research topic was reflected in the complexity of the cases, specifically in relation to the multiple meanings and understandings attributed to ACP that were identified by exploring various perspectives and data sources.

## 46 Implications for the Nursing Profession

The main implication of this work in the context of nursing practice is the finding that ACP is a relational practice that is influenced by the priorities of the current neoliberal society, the institutional values of healthcare systems, and the relationships that exist among patients themselves, their SDM, and their HCP. Clinical practices that seek to promote autonomy (i.e. informed consent & ACP) need to be re-imagined using a relational understanding of autonomy

in order to capture the social and relational nature of decision making and care planning in chronic illness so these practices can become useful and relevant for patients and providers alike. Because the development of ACP has been heavily influenced by the biomedical model, there is often a narrow focus on decision making that exclusively emphasizes treatment options at EOL and specifically focuses on resuscitation status (Killackey et al., 2019a; Killackey et al., 2019b). This treatment and intervention-oriented approach is incongruent with the broad ideals of nursing, which support a holistic approach to enhancing the well-being of people and their families (Killackey et al., 2019a). Focusing exclusively on biomedical treatments may lead to a lack of appreciation for the conversations and interactions that nurses have with patients and their families about a person's life goals that are not directly related to treatment choices, such as personal and family-oriented goals (Killackey et al., 2019a).

ACP should be a continuous process of exploring values and goals throughout the course of a chronic illness and includes patients, family members and a variety of HCP (Killackey et al., 2019a). One of the main barriers to nurses' involvement in ACP is the misconception that ACP discussions should only be conducted by physicians (Izumi, 2017), and this may be one reason why staff nurses were not identified in this study as being closely involved in the ACP process. However, HCP who communicate about ACP with patients and family members and support them in thinking about what is important to them do not need to be physicians (Killackey et al., 2019b). Rather, nurses are in an optimal place to facilitate this process, as they are the healthcare professionals closest to patients and are well-positioned to act as "decision coaches" (You et al., 2017, p. 789; You et al. 2015; Izumi, 2017; Ke, Huang, O'Connor & Lee, 2015). As Ke et al. (2015) note, a nurse plays crucial roles in ACP as "assessor, initiator, information provider, communicator, advocate, broker, supporter, educator and manager" (p. 2067). There is currently no one service, provider or profession who is solely responsible for the provision of ACP. However, as nurses are often the mediators of the patient, family and healthcare team dynamics, and are often responsible for sharing patient priorities with the healthcare team, this is an especially important area in which nurses should take on further responsibility. Specifically, by viewing autonomy as a broader, relational concept and by embedding serious illness conversations within care routines and processes, nurses can support the goals of patients and their families that are not necessarily focused exclusively on cure or the pursuit of biomedical

treatment (Strachan, Kryworuchko, Nouvet, Downar & You, 2018). Overall, nurses should develop competence and confidence in communicating with patients and families, and learning how to best support SDMs who are making challenging decisions (Killackey et al., 2019b).

As discussed, ACP is an inherently relational process as it relies heavily on the involvement of at least one SDM (and frequently involves many interpersonal relationships), as well as the involvement of key HCPs. Informal caregivers play a major role in HF management (Buck et al., 2015; Waterworth & Gott, 2010), and therefore patients experience EOL decision making as a social process where they are most concerned about relieving the burden placed on loved ones and are willing to provide surrogates and caregivers with leeway when making challenging health decisions on their behalf (Johnson et al., 2016; Singer et al., 1998; Sudore & Fried, 2010). This study has demonstrated the current documentation-focused process of ACP incorrectly assumes that patients have sufficient self-awareness to clearly articulate very complex values and sufficient self-trust and self-confidence to express these values to family members and HCP, even if they are in conflict with biomedical and societal norms. Based on this finding, there is an important role for nurses to act as mediators and translators, and support patients to understand their disease and treatment options, develop their self-knowledge and self-trust in the decision making process, and identify and articulate their values to the healthcare team in a meaningful way. Moreover, there is a need for nurses to provide ACP in a way that is targeted not only to individual patients, but that also recognizes the role and responsibility of SDMs and accounts for the influence of the social, political, and environmental forces that surround the patient and family.

Finally, a relational understanding of autonomy, given its basis in feminist ethics, can encourage nurses to critically analyze not only the goals of ACP, but the overall goals of healthcare by locating these goals within a sociopolitical context (Killackey et al., 2019a). Van Heijst (2009) contrasts today's dominant paradigm of healthcare as that of "restoring health and prolonging life" (p. 200) as opposed to what they hope will be the paradigm of the future: "professional relief of suffering in accordance with the patient's own good" (p. 200). They argue that the latter would involve coming to terms with the transience of human existence and providing acceptance and care for those who are dying and in pain (van Heijst, 2009). Their perspective has the

potential to widen our understanding of ACP to ensure that nurses and others recognize the overall goals of care, especially for those who are elderly and living with multiple chronic conditions (Killackey et al., 2019a). Nurses may underestimate their societal power and ability to influence or change the values that direct healthcare, but using a relational lens may allow nurses to shift from an individualized perspective and instead promote autonomy as an interdependent experience, as outlined by Greaney's recent empirical work (Greaney & O'Mathuna, 2017; Killackey et al., 2019a). This model rejects the idea that autonomy is exerted through "discrete moments and choice", and instead puts forth an understanding of autonomy as an interdependent process that "involves mutual respect and understanding between patients and professionals" (Greaney & O'Mathuna, 2017, p. 94). Nurses, as the professionals that provide constant care and define themselves in terms of relationships of close proximity to patients (Peter & Liaschenko, 2004), can work to promote this relational view and align the clinical process of ACP with the daily experiences of patients and families.

## 47 Implications for Practice

These study findings suggest that an alternative model of relational autonomy may be used to develop ACP and EOL decision making in a way that can meaningfully build on the existing model of autonomy that patients and families experience throughout the illness trajectory. When considering the education of future HCPs, there has been research done on alternative models of decision making that may be relevant to briefly examine; specifically, the model of Shared Decision Making (Charles, Gafni & Whelan, 1997). This model may support different approaches to understanding decision making that are not based solely on individual autonomy and offer alternative strategies for HCP to navigate the complexities of clinical decision making.

Shared decision making emerged as a way to improve patient care by encouraging the dissemination of accurate, balanced, understandable health information and increasing patient participation in the decision making process (Lin & Fagerlin, 2014; Charles et al., 1997). Shared decision making holds the following requirements: there is involvement of two or more participants, and each party is involved in the decision making process and freely shares information with the other (Lin & Fagerlin, 2014). This model of decision making views the provider's responsibility as providing accurate medical information, eliciting and acknowledging

patients' preferences for participation and giving patients choices about how the decision making process unfolds (Légaré & Witteman, 2013; Lin & Fagerlin, 2014). Patients have the responsibility to communicate their values, goals, and preferences to their SDM and HCP, and both parties agree to the decision when a treatment decision is made (Lin & Fagerlin, 2014).

At first glance, shared decision making sounds quite similar to the ACP process, and seems to share the goal of incorporating patient preferences, goals and values into health decision making. A key difference is that ACP is primarily associated with EOL care, whereas shared decision making does not have this connotation. If shared decision making was routinely and fully integrated and implemented in our healthcare systems, there may not be a need for the specific process of ACP, as decision making partnerships would be established earlier in the illness trajectory. Unfortunately, that is not the case, as shared decision making has suffered from challenges similar to ACP, and despite some success implementing this practice in specific contexts, shared decision making is still not routine in most healthcare systems (Joseph-Williams et al., 2014; Elwyn et al., 2013; Brom et al., 2017)

In their 2014 systematic review, Joseph-Williams et al. (2014) highlighted that the key barriers to shared decision making concern both information and power. First, they identified an “information paradox” in the decision making process, whereby patients require information to participate in shared decision making, but due to the dominant view that physicians are experts, patients may not appreciate their ability to acquire the complex biomedical knowledge that is “owned” by physicians (p. 307). This observation aligns closely to the results of my study that demonstrated the impossibility of being informed in the biomedical context and the limited role that patient expertise (i.e. personal experience, preferences and goals) factor into the treatment decision making process. Second, echoing the findings of this study on ACP, the authors noted that due to the deep power imbalance that characterizes the doctor–patient relationship, “information provision and encouragement to value personal contribution alone are unlikely to promote shared decision making for most patients” (Joseph-Williams et al., 2014, p. 307). Similarly, the authors found that many patients engaged in an unspoken contract with their HCP and strived to be considered good patients, a role that was characterized by passivity and compliance, or, as was found in my study, patients accepting the treatments that were offered to them due to their debt of gratitude (Joseph-Williams et al., 2014).



Overall, the authors concluded that “knowledge is not power” in the context of shared decision making, and rather that patients require *both* knowledge and power to effectively participate the decision making process (Joseph-Williams et al., 2014, p. 307). The strong influence of biomedical power may explain why many patients actually *cannot* participate in shared decision making or ACP, as opposed to the predominant narrative that patients simply choose not to participate because they do not want to engage or think about EOL. This work, along with the current findings of this study, demonstrate the power of normative beliefs and social discourses that shape the ACP process, which are unlikely to be addressed by individualized interventions that focus solely on education or behaviour change.

## 48 Implications for Education

The results of this study also have important implications for the education of health professionals from a variety of disciplines including nursing, medicine, social work, and bioethics. The knowledge generated by this research can be used to educate care providers in HF care so they can be better prepared for the complexity of their role in communicating and guiding care decision making and supporting autonomy for their patients with complex chronic illness. This study calls attention to the nuanced pressures that both HCP as well as patients and families experience within the social structure of the healthcare system and the need to re-evaluate the understanding of autonomy used to justify the practice of ACP. Providers guided patients through the complex experience of living with advanced HF and attempted to balance their duties and responsibilities at the individual level with broader social, legal and political implications. Constrained by the guideline-oriented nature of HF treatment, providers struggled to maintain a balance between providing biomedical management and acknowledging the terminal nature of the disease. Educating clinicians about the broader interpersonal power dynamics and social forces that shape decision making in advanced HF, and the ways this process may not align with the traditional conceptualization of autonomy, may allow providers to understand the nuances associated with practices such as ACP, beyond merely attempting to determine “what the patient wants”.

In addition, the current education of future healthcare professionals and health researchers presents the “hierarchy of evidence” as the dominant way to conceptualize the value of various

research designs and methodologies, and the rhetoric of evidence-based practice within current health systems is an overpowering force in the clinical and health research landscape (Rycroft-Malone et al., 2004; Holmes, Murray, Perron & McCabe, 2008). The combination of these two discourses contributes to an overarching focus on quantitative, randomized controlled trials as the gold standard for generating evidence to construct guidelines and protocols (Rycroft-Malone et al., 2004). The cumulative result is that research involving qualitative design to examine the experience and expertise of patients and families is relegated to the “bottom” of the pyramid, if included at all. The additional influence of drug and device companies, who are often involved in the funding and design of these studies (Fabbri, Lai, Grundy & Bero, 2018), can also drive the research agenda and lead to an overemphasis on the benefits of these drug and device related therapies. Interestingly, as highlighted in this study, this influence can also lead to lack of robust data for sub-populations (such as older adults), as companies maintain a certain “opacity” of data in order to increase use of their therapies. Ultimately, future health professionals and health researchers should be educated on the way these guidelines and protocols are developed, be provided transparent information regarding the involvement and vested interests of the various organizations that fund this type of research, and be taught the immense value of qualitative research as a means to understand and answer questions that quantitative designs are unable to answer (Ma, 2000; Morse, 2005; Watkins, 2012).

Finally, it is also imperative to educate both current and future professionals on alternatives to the traditional model of informed consent and demonstrate how to integrate strategies such as shared decision making and developing patients’ sense of self-trust into the clinical context. As mentioned, although patients’ experiences did not align with traditional individual autonomy, patients and their family members did not seem upset or concerned with the way decisions were taking place, which was primarily using a relational model based in trust. Because they were comfortable with HCP-directed care, it could be argued that the problem arises when HCP do not allow EOL decisions to continue to be made using a HCP-directed relational model, and instead try to force an individualized model of autonomy onto patients and families at their most vulnerable moments. There is a risk that ACP is susceptible and will continue to be susceptible to the same criticisms and challenges of the process of informed consent if it continues to be underpinned by the principle of individual autonomy. Professional associations, such as the

American Heart Association, endorse a model of shared decision making for cardiac patients, which is enacted through a series of meetings or discussions between the patient, family and HF care team (Allen et al., 2012; MacIver & Ross, 2018). In this framework the role of the clinician is to summarize the patient's prognosis, including information on potential treatment outcomes, quality of life, symptom burden, caregiver burden and the types of challenges and decisions the patient may face in the upcoming year (Allen et al., 2012; MacIver & Ross, 2018). Together the patient, family and HCP team determine the goals of care and decisions may be enacted immediately or in the future and are subject to change based on the patient's condition. Educating future providers on the importance of this type of model, while focusing on providing patients with *both* power and knowledge in the healthcare encounter (Joseph-Williams et al., 2014), may allow patients and family members to develop autonomy competencies throughout the course of the illness, build decision making capacity in SDMs, and serve to level the power dynamics that exist within the professional relationship.

## 49 Implications for Policy

In 2006, Health Canada released the final report on *Advance Care Planning: the Glossary Project* which sought to bring clarity to the concepts and terms used in advance care planning in Canadian provinces and territories and in the health, social and legal sectors in order to facilitate national dialogue about ACP (Health Canada, 2006). This project was developed because ACP had been identified as a priority issue by the Public Information and Awareness Working Group of the *Canadian Strategy on Palliative and EOL Care* (Health Canada, 2007). The report examined concepts and terms and the ways in which they are understood by professionals and the public, and also provided an overview of experience with ACP in Canada (Health Canada, 2006). Although many of the conclusions of this report aligned with the results of this study and focused on the interpersonal level of determining patient wishes and facilitating discussion of treatment preferences, there was also indication that broader systemic change was required in order to support ACP, specifically in relation to improving communication and documentation through standardized approaches to ACP (Health Canada, 2006). Overall, the major outcome of this project was the implementation of the National Advance Care Planning Task Group, who subsequently developed the first national framework on advance care planning in Canada

(Advance Care Planning in Canada, 2012). A key action item in response to this framework was the development of the Speak Up program, a national campaign launched in 2013 to enhance participation in ACP across Canada and provide resources for the public and for professionals.

More recently, this national framework was updated and the *Pan-Canadian Framework on Advance Care Planning 2020* was released with the goal of moving Canadians from “thinking that Advance Care Planning is a good idea to actually having those important conversations” (Advance Care Planning in Canada, 2020, p. 2). While the original 2012 framework was focused on individual autonomy as a key ethical principle in the development of ACP, the recent 2020 framework has shifted to using the term “relational autonomy” and incorporates a brief discussion of this concept by highlighting the following key points regarding relational autonomy in ACP:

1. Autonomy emerges within and because of relationships; in situations of care, a person is able to plan and/or make care decisions through their interdependence on loved ones, families, communities, care providers, institutions, and systems.
2. Advance Care Planning focuses not only on what possible decisions might be made but also who will be making decisions and how they will be made.
3. Conversations address people’s relational concerns about ACP, for example, burdening their Substitute Decision Makers to follow their wishes; balancing control over future decisions with trust in their Substitute Decision Makers; or disrupting customary patterns of decision making within their family or community.
4. A relational approach to ACP and Goals of Care conversations is fostered within health care settings by patient-and-family-centered care, Supported and Shared Decision Making, patient advocates and navigators, and other collaboration-based practices.

Advance Care Planning in Canada: A Pan-Canadian Framework, 2019 p. 37

Highly relevant to this study, this overview aligns closely with the empirical findings of this research that highlight how autonomy is exercised within relationship of interdependence, care and trust (Sherwin, 1992; McLeod & Sherwin, 2000; Mackenzie & Stoljar, 2000; McLeod, 2000). Although exciting to see this recent shift in the conceptualization of

autonomy from traditional individualism towards a relational understanding in the context of ACP at the national level, the framework holds the assumption that relational autonomy is currently being supported in the clinical setting through various “collaboration-based practices” (p. 37) such as supported and shared decision making. Unfortunately, this message fails to acknowledge the dominance of individual conceptualizations of autonomy that underpin the current policies and practices that guide treatment decision making and minimizes opportunities to examine how to better support relational autonomy within the ACP process (Advance Care Planning in Canada: A Pan-Canadian Framework, 2019 p. 37). The results of this study could help developed a more nuanced understanding of how relational autonomy is experienced within the ACP process, and more specifically, how broader institutional and social forces as well as interpersonal and social power dynamics shape the experience of ACP, which could strengthen this national framework.

In regard to broader policy on palliative care, in 2018 Health Canada released the *Framework on Palliative Care in Canada*, which was developed through consultation with provincial, territorial and national stakeholders, along with people living with life-limiting illnesses, their caregivers and other Canadians (Health Canada, 2018). Although this framework is quite broad, it specifically describes the negative implications of intensive intervention at the EOL as both costly and ineffective, and also highlights the centrality of patient autonomy in decision making and care planning by stating that it is the responsibility of citizens to “express their perspectives/needs/preferences to guide their own care plans” (Health Canada, Framework on Palliative Care in Canada, 2018 p. 10). This messaging clearly mimics the neoliberal rhetoric of responsibility and self-management and extends this requirement to citizens to manage their own care right up until the time of death. Following this, in early 2019, the Canadian federal government released their *Action Plan on Palliative Care*, which builds on this framework and presents Health Canada's five-year plan to tackle issues identified through previous consultations as part of the framework. This action plan “aims to improve quality of life for people living with life-limiting illness, families and caregivers, and enhance access, quality of care and health care system performance” by focusing on five key goals (Health Canada, 2019, p. 2). Two of these goals have specific relevance to the process of ACP: (1) Raise awareness and understanding of how advance care planning and palliative care can improve quality of life until the EOL; and (2)

Foster improved access to palliative care for underserved populations, which includes supporting the development of culturally and linguistically appropriate tools that increase discussions about advance care planning (Health Canada, 2019).

By examining the way ACP is experienced by chronically ill patients, these study findings contribute a novel perspective that could strengthen the response to this action plan which seeks to support the development and uptake of ACP across Canada. Future policy initiatives must consider how the concept of ACP is understood and approached by patients and providers alike: as something that is external to treatment decision making and closely associated with death and, therefore, is quite different than the way this process is defined in the current research literature. Because of the dominance of the legal and biomedical models in understanding ACP, there is an overarching focus on documentation such as resuscitation status, wills, etc. that may not directly influence the care patients receive in the months and years prior to death. Additionally, the substantial influence of current rhetoric of “evidence-based practice” and the guideline-driven standardization of HF care should be acknowledged as a potential barrier to the implementation and uptake of ACP practices in current healthcare settings. Future policies around ACP and palliative care will have to address the skepticism that both the public and HCP hold regarding the ability of ACP to achieve its stated goals.

Moreover, policies that claim to support patient autonomy and encourage empowerment may need to address how autonomy is experienced by patients throughout the illness trajectory, in order to develop a nuanced understanding of how the practice of ACP may align more closely with patients’ and their families’ needs. Future policies related to ACP and palliative care more broadly may need to be more sensitive to what it means to die of a chronic disease within the modern healthcare setting and acknowledge the increasing availability of devices, procedures and invasive therapies, especially in the context of advanced HF. This trend in practice may support the continued push for biomedical treatment while simultaneously allowing practitioners and patients to avoid the acknowledgement of potential death, even for those at an advanced age or living with end-stage disease. Limited time and increasingly scarce healthcare resources continue to be significant problems in many healthcare systems as the population of older adults grows and the complexity of patients continues to increase (Fowler & Hammer, 2013). In addition to advocating for increased time to spend communicating with complex HF patients and

modifications in training to support ACP, as has been suggested in previous studies (Ahluwalia et al., 2012; Ahluwalia et al., 2013; Ahluwalia & Enguidanos, 2015; De Vleminck et al., 2014; Chandar et al., 2016; Gigon et al., 2015; Zwakman et al., 2018), this study suggests that an overall shift in the dominant paradigm of the biomedical model to a broad, holistic and relational understanding of the patient experience is needed to support uptake of the ACP process (Killackey et al., 2019a; Killackey et al., 2019b).

Finally, the results of this study have implications within a broader global context. Many high-income countries are struggling with growing healthcare costs at the EOL, especially for the complex population of advanced HF patients, and are looking to ACP as a means of addressing these concerns while supporting patient autonomy (Lund & Savarese, 2017; Cook, Cole, Asaria, Jabbour, & Francis, 2014; Warraich et al., 2017). By shifting our understanding of ACP towards a process that is grounded in relationality, researchers, HCP and policy makers in global settings can better align ACP policies, practices and legislation with the social experience of patients, family members and clinicians. HCP can operationalize a relational conception of autonomy by advocating for policies and legislation that broaden our understanding of autonomy beyond the concept of consent and promoting models of supported and shared decision making (Greaney & O'Mathuna, 2017; Killackey et al., 2019a; Sherwin & Stockdale, 2017; Dove et al., 2017). On a global front, The United Nations Convention on the Rights of People with Disabilities (2006) obliges member states to provide citizens with measures to assist them in their decision making (Arstein-Kerslake et al., 2017). This has led to change in health and social care practices in many countries; an example of this is the Assisted-Decision Making (Capacity) Act that was passed in Ireland, which outlines the implementation of supportive measures to assist individuals to make their own decisions (Arstein-Kerslake et al., 2017). Other examples of this type of work have been seen taking place locally and globally (Arstein-Kerslake et al., 2017). In Canada, the Canadian Association for Community Living (CACL) Taskforce highlighted the importance of supported decision making by suggesting substituted decision making legislation was based on a "misconception that personal autonomy can only be exercised independently" (p.2). The group instead proposed supported decision making as an alternative conceptual framework for decision making, which recognizes that personal autonomy can be expressed interdependently, which aligns with the tenets of relational autonomy. By combining new legislation that supports

assisted decision making with a relational understanding of autonomy as a negotiated and interdependent process, HCP should further develop supported decision making policy and practice in order to strengthen the autonomy of their patients in a variety of contexts (Killackey et al., 2019a).

## 50 Implications for Research and Future Directions

Although institutionalized ACP has existed within healthcare systems for more than 30 years, it continues to be a challenge to implement and sustain. This research has added to the field by describing the experiences of HF patients, family members and healthcare providers in relation to the ACP process as a component of chronic illness management and a means to exercise autonomy. Most significantly, this research has highlighted the social and relational nature of ACP and EOL decision making for patients living with HF and exposed the current incongruity between the individualistic underpinnings of ACP as it is often conceptualized in clinical practice and the relational reality experienced by patients, family members and HCPs.

The findings of this study also align with other empirical research which demonstrates that from the patient perspective, ACP functions less as an individual directive and more as a family-centred, relationship-driven process (Johnson et al., 2016; Robins-Browne et al., 2017; Lin et al., 2018). Recommendations for future research include inquiry into the experiences and perspectives of patients and SDMs regarding the contextual factors that influence the uptake of ACP, the effect of ACP on interpersonal relationships, and examining the experience of ACP and subsequent substitute decision making specifically from the perspective of SDM and family members would be beneficial (Andreassen et al., 2015; Shapiro, 2015).

This research has demonstrated the need for researchers to examine the complex topic of ACP and the experience of chronically ill patients using theory and methodology that are congruent with the reality of patients and that allows researchers to account for relevant social and relational factors. The combination of empirical data gathered in this study and the theoretical analysis of relational autonomy developed through this work serves to demonstrate the way current processes of ACP are misaligned with the priorities of patients and families who are approaching or planning for the EOL. Future research should examine how relevant self-referring attitudes, such as self-trust, may work to influence patients' experiences of the ACP



process, and how these autonomy-enhancing competencies and attitudes may be better developed and promoted in the Canadian healthcare setting. Further empirical work is also required to explore how relational conceptions of autonomy may allow us to better understand and improve the experience of ACP for patients with a diverse range of chronic illnesses, and further, how this approach may improve health decision making in a broader context throughout the illness trajectory.

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# Appendices

## Appendix A: New York Heart Association (NYHA) Classification System

Class	Patient Symptoms
I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

## Appendix B: American Heart Association (AHA)/American College of Cardiology (ACC) Heart Failure Staging Classification

Class	Objective Assessment
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.



## Appendix C: Eligibility Criteria for Literature Review

### **Eligibility Criteria for Study Inclusion:**

1. Reports on advance care planning or treatment preferences for EOL care (this may include CPR, mechanical ventilation, etc.)
2. Is original empirical research or recent strong systematic review
3. Involves cardiovascular patients (ideally heart failure) plus or minus healthcare providers and caregivers
4. Involves competent adults (No pediatrics, no dementia, etc.)
5. Reports on:
  - a. Studies examining ACP practices, implementation, interventions, prevalence, or awareness in the cardiovascular population
  - b. Studies examining the perspectives, experiences, or EOL preferences of patients with heart failure, their family members or their healthcare providers

## **Appendix D: Participant Inclusion Criteria**

### **Patient Inclusion Criteria**

Patients will be potentially eligible for this study if they meet all of the following inclusion criteria:

1. Has advanced (NYHA III-IV) heart failure
2. Appears relatively stable in their overall condition, i.e. lives at home and is able to ambulate.
3. Appears cognitively intact and is able to provide consent for the study.
4. Able to speak and read English.

Patients who fulfill all of the inclusion criteria will be approached for the study.

### **Patient Characteristics**

This study is looking for patients from different backgrounds. Efforts will be made to recruit patients that have a variety of these characteristics

- Gender
- Age
- Cultural background
- Employment
- Family structure
- Religious background
- Education level
- Severity of heart failure
- Length of illness
- Treatment mode (i.e. device usage)

## Appendix E: Study Introduction Script

We have a PhD candidate from the nursing department at the University of Toronto who is conducting a research project about the experiences of people who have been treated for heart failure. This study is about how patients and their families make decisions regarding current and future healthcare and treatment options. It is also about how people plan for the times when they may become sick. Because of your healthcare experience here, you have been identified as someone who could participate in this study. If you are interested, you would be asked to do a one hour interview about your experiences living with heart failure. There is a possibility of a follow up interview. The interview would take place at a place and time of your convenience, which could be here in the hospital, at your home, or in a public meeting place. Can we give you the information package about this study? There is more detailed information including all of the questions that you would be asked in the interview. Agreeing to receive this package does not mean that you are going to be in the study. The study has been approved by the Research Ethics board.

The PhD student is here in the hospital. Would you be interested in speaking to her in person to explain the study in more detail? If not, would you like to write your name, email and phone number on this sheet and sign it? Then she will follow up with you in a couple of days to see if you have any questions.

## Appendix F: Interview Guides

### Interview Guide for Patients and Family Members

The purpose of this interview is to talk to you and your loved one(s) about your heart failure journey, experience making healthcare decisions and your participation in advance care planning. I just want to remind you that if there is any time you want to take a break, or if you want to stop all together, just let me know and we will respect that. If there is any question you don't want to answer, you don't have to answer them.

What questions do you have before we begin?

1. Tell me a little bit about yourself and your family?
2. Tell me a bit about what is most important to you in life right now?
3. What has it been like for you/your family to live with heart failure?
  - a. What was it like for you/your loved one to be diagnosed?
  - b. What experiences have been especially important since being diagnosed?
4. What decisions have you made about your/your loved ones' healthcare?
5. What decisions have you made regarding your life since being diagnosed?
6. What were some important factors you considered when making these decisions?
7. Who helped you make these decisions?
8. Have you heard about advance care planning? What does that mean to you?
  - a. Do you have a power of attorney for personal care?
  - b. Living will or advanced care directive?
  - c. If yes, when did you start thinking about doing this type of documentation?
  - d. If no, can you tell me a bit more about why not?
  - e. What do these documents mean to you?
9. Some people tell us that it can be hard to talk to their family members about advance care planning. What have these conversations been like?
10. What personal values, personal priorities or beliefs help you make decisions?
11. What helps you make important decisions in your life?
12. How have you felt about participating in this research/interview?

## **Interview Guide for Healthcare Providers**

The purpose of this interview is to talk to you about your experience helping patients and their families make healthcare decisions and your participation in advance care planning. I just want to remind you that if there is any time you want to take a break, or if you want to stop all together, just let me know and I will respect that. If there are any question you don't want to answer, you don't have to answer them.

Do you have any questions?

1. Tell me a little bit about yourself and your role as a cardiologist/nurse practitioner/nurse in the heart function program?
2. What do you think are the important decisions that have to be made by patients with advanced heart failure?
3. What is it like for you to work with patients with advanced heart failure?
4. What are your relationships like with them and their families?
5. Can you explain ACP for me? What's the process, what are the important elements? What types of resources are available to you to support advance care planning activities with patients within this hospital?
6. How did you learn about advance care planning?
7. What experience do you have participating in advance care planning with patients and families?
  - a. Are there some examples you could provide of these experiences?
8. How do you document advance care planning conversations and/or decisions?
  - a. Can you tell me what you do when you see a patient has their wishes documented?
9. What do you think influences patients to participate/not participate in advance care planning discussions?
10. What do you think is most important to heart failure patients who are participating in advance care planning?
  - a. What personal values, personal priorities or beliefs do you think help patients make decisions?

## Appendix G: Participant Information Form

1. What is your relationship to the patient?
  - a. I am the patient
  - b. Spouse
  - c. Daughter/Son
  - d. Other relative
  - e. Friend
  - f. \_\_\_\_\_
2. What is your age? \_\_\_\_\_
3. How long have you or your family member been living with heart failure?  
\_\_\_\_\_
4. How long have you been coming to this clinic? \_\_\_\_\_
5. Has the patient been admitted to the hospital in the past six months? Yes/No
  - a. If yes, how many times? \_\_\_\_\_
6. Do you have any medical devices such as a pacemaker or ICD? Yes/No
  - a. If yes, which device do you have? \_\_\_\_\_
7. Do you have a written Power of Attorney for Personal Care? Yes/No
  - a. If yes, who is it? \_\_\_\_\_
8. Do you have a written advance care directive or living will? Yes/No
  - a. If yes, have you discussed it with anyone? Yes/No
  - b. If yes, who have you discussed it with? \_\_\_\_\_
9. Have you ever been a substitute decision-maker and needed to make treatment decisions for someone else? Yes/No

