

COMPARING ENGAGEMENT IN ADVANCE CARE PLANNING BETWEEN
STAGES OF HEART FAILURE

Lori A. Catalano

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Doctoral Committee

Susan Hickman, PhD, Chair

Diane Von Ah, PhD, RN, FAAN

December 14, 2018

Alexia Torke, MD

Michael Weaver, PhD, RN, FAAN

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DEDICATION

This dissertation is dedicated to my mother, Teri Catalano, who always told me that I would be successful in anything I wanted to do. Rest in peace, Mom.

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As I finish this, I'm reminded of the book by Dr. Seuss, *Oh, The Places You'll Go*: "Today is your day. You're off to Great Places! You're off and away!"

Lori A. Catalano

COMPARING ENGAGEMENT IN ADVANCE CARE PLANNING BETWEEN
STAGES OF HEART FAILURE

Heart failure is a terminal disease with an unpredictable trajectory. Family members of patients with heart failure are often called upon to make decisions about treatment and end of life care, sometimes with little guidance as to the patients' wishes. Advance care planning (ACP) is an ongoing process by which patients make decisions about their future healthcare. Only about one-third of patients with heart failure have participated in ACP, which is a similar percentage to the overall population. Despite increased focus on ACP and interventions to improve it, the rates of ACP in the population remain relatively unchanged. There is a need to develop interventions that are targeted based on patient engagement in the process rather than the existing broad-based interventions.

The purpose of this dissertation study is to examine the relationship between the American Heart Association stage of heart failure and readiness to engage in advance care planning. The study consisted of mailed surveys that consisted of demographic questionnaires and the Advance Care Planning Engagement Survey. Engagement was analyzed in relation to heart failure stage, heart failure class, comorbidities, perception of health status, recent hospitalizations, making healthcare decisions for others, and demographic variables. The results demonstrated that although there was no significant association between heart failure stage or class and engagement in advance care planning, there were significant associations between medical comorbidities and advance care planning engagement. Other significantly associated participant characteristics included

age, gender, education, ethnicity, and income. Findings suggest that people with multiple comorbid conditions will be more likely to be ready to engage in ACP than those with fewer health conditions. The results from this study will contribute to the development of strategies to improve advance care planning that are targeted based on engagement level.

Susan Hickman, PhD, Chair

TABLE OF CONTENTS

List of Tables	xi
List of Figures	xii
List of Abbreviations	xx
Chapter 1: The Nature of the Study.....	1
Background and Significance.....	1
Statement of the Problem.....	3
Research Aims.....	10
Chapter 2: Literature Review and Conceptual Framework	13
Overview of Heart Failure	13
Classes and Stages	14
Trajectory of Heart Failure.....	16
Costs of Heart Failure	17
The Joint Commission and Other Recommendations.....	17
Advance Care Planning	19
Advance Care Planning Documentation Tools	19
Advance directives	19
Code status orders.....	20
Physician Orders for Life-Sustaining Treatment (POLST)	20
The Origin of Advance Care Planning.....	21
The Shift to Advance Care Planning as a Process.....	25
Effects of Advance Care Planning.....	26
Advanced directive completion.....	26
Care congruent with patient wishes.....	27
Satisfaction with care.....	28
Improvements in end-of-life care	29
Benefits to surrogates	31
Financial effects	32
Barriers to Advance Care Planning	32
Patient barriers.....	32
Provider barriers	34
Advance Care Planning in Heart Failure	35
Conceptual Model	36
Trans-Theoretical Model.....	36
Model of Engagement in Advance Care Planning	37
Health Variables	38
ACCF/AHA heart failure stage and NYHA heart failure classification.....	38
Comorbidities	38
Patient perception of health status.....	39
Patient Experiences.....	39
Recent hospitalizations	39
Making healthcare decisions for others	40
Sociodemographic Variables.....	40
Age.....	40
Gender.....	41

Ethnicity	42
Marital status	43
Income	43
Education	43
Religion.....	44
Health literacy	44
Engagement in Advance Care Planning.....	44
Advance Care Planning Engagement Survey	47
Summary	50
Chapter 3: Methods	52
Design	52
Research Aims.....	52
Setting	54
Sampling	54
Sample Size	56
Human Subjects Protection.....	57
Measures	58
Engagement in Advance Care Planning.....	58
ACCF/AHA Heart Failure Stage and NHYA Heart Failure Class.....	60
Comorbidity.....	61
Perception of Health Status	62
Recent Hospitalizations.....	62
Sociodemographic Variables.....	63
Health Literacy	63
Study Procedures	64
Data Analysis	65
Chapter 4: Results	72
Specific Aims and Hypothesis Testing.....	72
Aim 1.....	72
Aim 2.....	82
Chapter 5: Discussion.....	89
Main Findings	89
Heart Failure Stage/Class and Advance Care Planning Engagement.....	89
Comorbid Conditions' Effects on ACP Engagement	90
Recent Hospitalizations.....	92
Making Healthcare Decisions for Others.....	93
Personal Perception of Health Status.....	93
Sociodemographic Variables and Engagement in ACP.....	94
Age, gender, marital status, education, and income	94
Ethnicity	95
Religious preference	96
Documentation: Surrogate Decision-Makers and Advance Directives	96
Summary	97
Implications for Practice.....	97
Future Research	99
Study Limitations	101

Conclusion	102
Appendices.....	103
Appendix A: Introduction Letter.....	103
Appendix B: Background Questionnaire.....	106
Appendix C: Advance Care Planning Engagement Survey.....	110
References.....	117
Curriculum Vitae	

LIST OF TABLES

Table 1: Definitions and ACP Behaviors in Trans-Theoretical Model..... 6
Table 2: Comparison of Stages and Classes of Heart Failure..... 15
Table 3: Predictor Variables 66
Table 4: Comparison of Survey Responders’ and Nonresponders’ Characteristics 74
Table 5: Demographic Characteristics of Participants 75
Table 6: Self-Reported Health Status of Participants..... 76
Table 7: Health Literacy of Participants..... 77
Table 8: Appointment of Surrogate Decision-Maker by Heart Failure Stage 79
Table 9: Discussion of Values and Goals of Care with Surrogate Decision-Maker by
Heart Failure Stage..... 80
Table 10: Discussion of Values and Goals of Care with Provider by Heart Failure
Stage 81
Table 11: Completion of Advance Directives by Heart Failure Stage..... 82

LIST OF FIGURES

Figure 1: Trans-Theoretical Model (TTM) of Behavioral Change.....	5
Figure 2: Algorithm for Living Will Completion, Showing Different Stages of Change...	7
Figure 3: Interaction of ACP Domains, Behavioral Processes, and Actions.....	8
Figure 4: Factors Affecting Engagement in ACP	10
Figure 5: Interaction of ACP Domains, Behavioral Processes, and Actions.....	48

LIST OF ABBREVIATIONS

ACCF	American College of Cardiology Foundation
ACHF	Advanced Certification in Heart Failure
ACP	Advance care planning
ACPES	Advance Care Planning Engagement Survey
AD	Advance directive
AHA	American Heart Association
ANOVA	Analysis of variance
CCI	Charlson Comorbidity Index
COPD	Chronic obstructive pulmonary disease
CPR	Cardiopulmonary resuscitation
DNAR	Do not attempt resuscitation
DNI	Do not intubate
DNR	Do not resuscitate
DPAHC	Durable Power of Attorney for Healthcare
EF	Ejection fraction
EOL	End of life
GWTG	Get With the Guidelines
HF	Heart failure
HFSA	Heart Failure Society of America
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
ICC	Intraclass Correlation

ICU	Intensive Care Unit
IOM	Institute of Medicine
IRB	Institutional Review Board
IU	Indiana University
IUPUI	Indiana University-Purdue University Indianapolis
M	Mean
MOLST	Medical Orders for Life-Sustaining Treatment
NYHA	New York Heart Association
OHVC	Ohio Heart and Vascular Center
POLST	Physician Orders for Life-Sustaining Treatment
PSDA	Patient Self-Determination Act
SD	Standard deviation
SDM	Surrogate Decision Maker
SF-36	Short Form Health Survey
SPSS	Statistical Package for the Social Sciences
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
TJC	The Joint Commission
TTM	Trans-Theoretical Model
VIF	Variance inflation factors

CHAPTER 1

THE NATURE OF THE STUDY

This study was designed to explore advance care planning in patients with heart failure. The main objective of this study was to examine the relationship between the American College of Cardiology Foundation/American Heart Association (ACCF/AHA) stage of heart failure, New York Heart Association (NYHA) class of heart failure, and engagement in advance care planning, as measured by the Advance Care Planning Engagement Survey (ACPES) (Sudore et al., 2017). This descriptive correlational study also examined patient characteristics that may predict engagement in advance care planning, including: gender; age; race/ethnicity; marital status; income; education; religion; health status; health literacy; and comorbid health conditions. Findings from this study provide information regarding factors that are associated with engagement in advance care planning. Ultimately, this research will be used to inform future research to develop targeted interventions to increase rates of advance care planning in patients with heart failure.

Background and Significance

It is estimated that approximately 5.7 million people in the United States are currently diagnosed with heart failure, with an additional 700,000 people newly diagnosed each year (Mozzafarian et al., 2016). Heart failure is one of the leading cause of hospitalizations in people aged 65 years or older and contributes to one of every nine deaths (Benjamin et al., 2017). The disease cost approximately \$31 billion annually in healthcare costs and lost employment days in 2012, and this cost is expected to increase to approximately \$70 billion by 2030 (Heidenreich et al., 2013).

A severe, insidious disease, heart failure (HF) is a terminal syndrome in which the heart is unable to meet the oxygenation demands of the body due to either structural or functional defects. Approximately one-half of those with heart failure will die within five years of diagnosis, typically as a result of sudden death from a lethal dysrhythmia (Mozzafarian et al., 2016). The remainder will experience a slow decline in health status over many years. Treatment of heart failure varies based on staging from the American College of Cardiology Foundation and the American Heart Association (ACCF/AHA), which leads to the need to reevaluate a patient's status on a regular basis to determine the appropriate, evidence-based therapy (Hammond et al., 2016). The American Heart Association periodically publishes clinical guidelines that recommend evidence-based therapy based on ACCF/AHA stage, including provision of advance care planning. The 2013 guidelines recommended that all cardiologists and other practitioners be comfortable with advance care planning in order to encourage it in their patients with heart failure (Yancy et al., 2013). This includes discussion of treatment options based on patient status and also consultations to palliative care if available (Yancy et al., 2013).

Advance care planning (ACP) is an ongoing process by which patients make decisions about their future healthcare based on their personal values, life goals, and preferences (Sudore et al., 2017b; Sudore et al., 2013). This process includes discussion of patient values, goals, and preferences with both family and healthcare providers. It may also include selection of a surrogate decision-maker (SDM) and the completion of advance directives (AD) (Sudore et al., 2017b; Piemonte & Hermer, 2013; Rogne & McCune, 2014; Sudore et al., 2013). ACP was formally addressed by the Institute of Medicine (IOM) in its publication, "Dying in America," in which the IOM panel noted

the need to “develop standards for clinical-patient communication and ACP that are measurable, actionable, and evidence based (IOM, 2014, p. 3). These standards would include routine discussion of prognosis, decision-making preferences, patient goals of care, and patient wishes for family involvement (Bernacki & Block, 2014). The Joint Commission also requires evidence of advance care planning to be reported as part of a hospital’s advanced HF certification (TJC, 2016).

Despite the endorsement of these organizations, approximately two-thirds of American adults have never engaged in advance care planning, and this proportion has remained relatively stable over the last several years (Benson & Aldrich, 2012; Stevenson & O’Donnell, 2015; Yadav et al., 2017). This number has been shown to be even lower in patients with heart failure. In 2012, one study found that 41% of patients with heart failure had ADs (Dunlay, Swetz, Mueller, & Roger, 2012), but another study in 2015 found that only 12.7% of these patients had ADs (Butler et al., 2015). More recently, Yadav et al. (2017) found that 38.2% of adults with chronic illnesses had completed advance directives, but did not examine the rates of completion by specific disease process.

Statement of the Problem

Advance care planning has been shown to have a variety of benefits, including increased likelihood others will know and follow the patient’s healthcare preferences, especially at the end of life (Detering et al., 2010; Johnson, Kerridge, Butow, & Tattersall, 2017; Sudore et al., 2013). It also is associated with decreased use of intensive medical therapies and increases the use of palliative interventions and hospice (Houben et al., 2014; Khan et al., 2014; Wright et al., 2008). Despite these benefits, many older

adults, including those with heart failure, have not participated in advance care planning to the extent that it is able to inform their healthcare; while they may have completed advance directives, the majority of older adults have not discussed their preferences with providers or family (Bond et al., 2018; Schickedanz et al., 2009). Several interventions have been developed to improve participation in ACP, but these interventions require an individual to be ready to engage in the process. This readiness to engage may depend on a variety of factors, including socioeconomic variables, a patient's other illnesses, and life events (Fried et al., 2010; Sudore et al., 2013).

One way to target future interventions is to determine a patient's stage of change related to engaging advance care planning. The Trans-Theoretical Model (TTM), introduced in 1986, describes change as a cyclical process containing stages through which people progress or regress (Prochaska & DiClemente, 1986). These stages of change are a way people adopt healthy behaviors; they include precontemplation, contemplation, preparation, action, and maintenance (Prochaska & DiClemente, 1986). These stage names reflect how a person can transition from a lack of knowledge or concern about a health behavior through the point of actively changing a behavior. Figure 1 (based on Prochaska & DiClemente, 1986) illustrates the stages of change based on the TTM. Engagement in ACP is one such health behavior to which researchers can apply the TTM. Because all health behaviors can be revisited, it is shown as a circle.

When applying the TTM to ACP, it is necessary to view ACP as a series of connected discrete behaviors rather than just one. ACP consists of discussing values and goals of care with loved ones, surrogate decision-makers, and providers (Sudore et al., 2013). It also includes completion of advance directives such as living wills and health

care proxy appointments (Sudore et al., 2013). A person's stage of change may vary depending on the behavior (Fried et al., 2010). Thus, a person may have discussed values and goals of care with loved ones, and be in the action stage for that behavior, but not yet ready to discuss them with providers, and be in the precontemplation stage for that behavior. Definitions of the stages and related ACP behaviors are in Table 1 (based on Prochaska & DiClemente, 1986 and Fried et al., 2010). Figure 2 illustrates examples of the different stages of change for completing a living will, one of the series of discrete ACP behaviors, taken from Fried et al. (2010).

Figure 1: *Trans-Theoretical Model (TTM) of Behavioral Change*

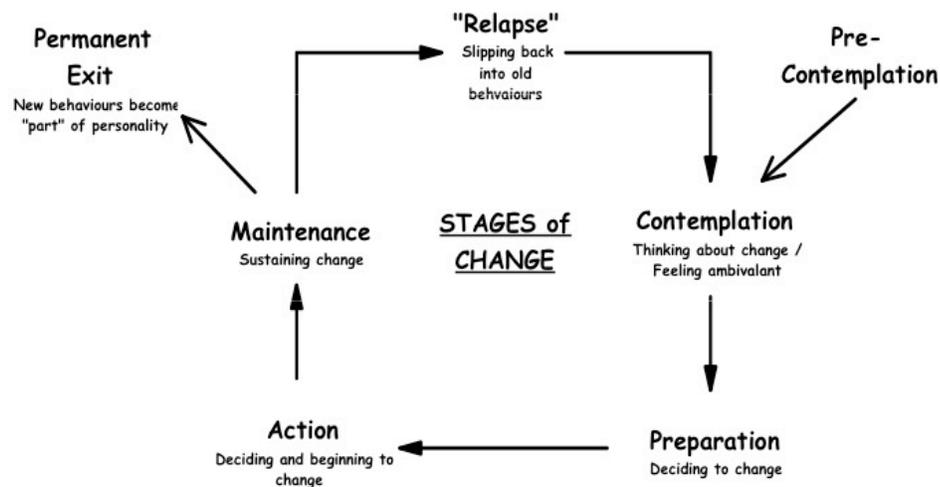
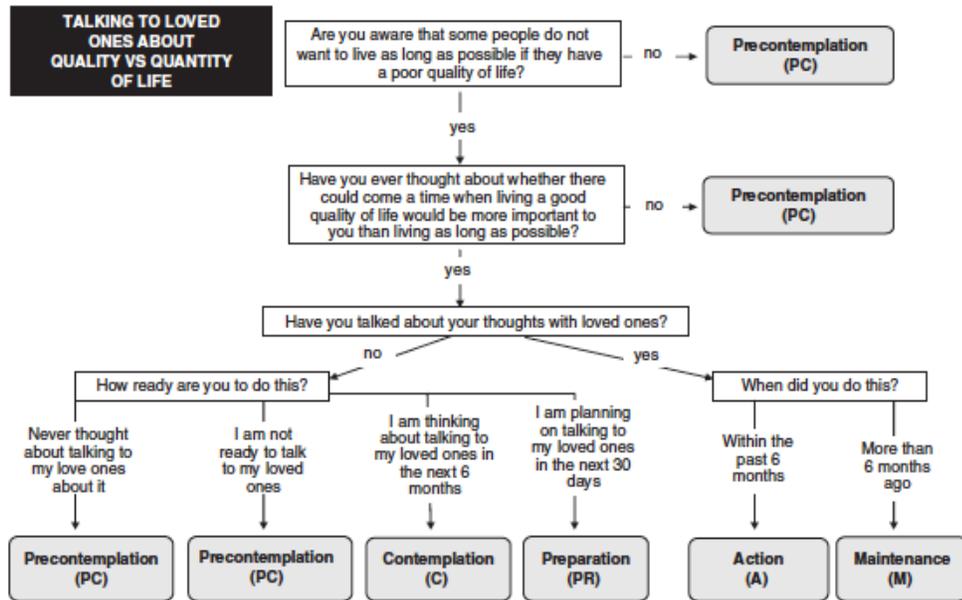


Table 1: *Definitions and ACP Behaviors in Trans-Theoretical Model*

Stage	Definition	Relevant ACP Behaviors
Precontemplation	No intention of changing behavior; possibly unaware of need for change	No associated behaviors; patient has not thought about ACP
Contemplation	Aware of need to change behavior, but no commitment to take action	Patient is thinking about engaging in some aspect of the ACP process in the next six months
Preparation	Intention to take action in the next thirty days	Patient is thinking about engaging in some aspect of the ACP process in the next thirty days
Action	Actual modification of the behavior or environment	Patient is speaking to loved ones and/or providers about values and goals of care; patient is documenting such goals of care. These behaviors are either actively ongoing or were done in the previous six months.
Maintenance	Stabilization of the new behavior over a period of time	Patient has spoken to loved ones and/or providers about values and goals of care and has documented such discussions. A surrogate decision-maker has been formally appointed. These behaviors have occurred more than six months ago.
Permanent Exit or Termination	No risk of returning to the old behavior; new behavior is permanent	Not applicable for many health behaviors. In ACP, may occur when patient loses capacity to engage in ACP and SDM begins to make decisions.
Relapse	Reversion back to previous unhealthy behavior; may occur at any time	May not occur in ACP or may reflect a change in health status that causes a need to revisit the cyclical process

Key: ACP = advance care planning; SDM = surrogate decision maker.

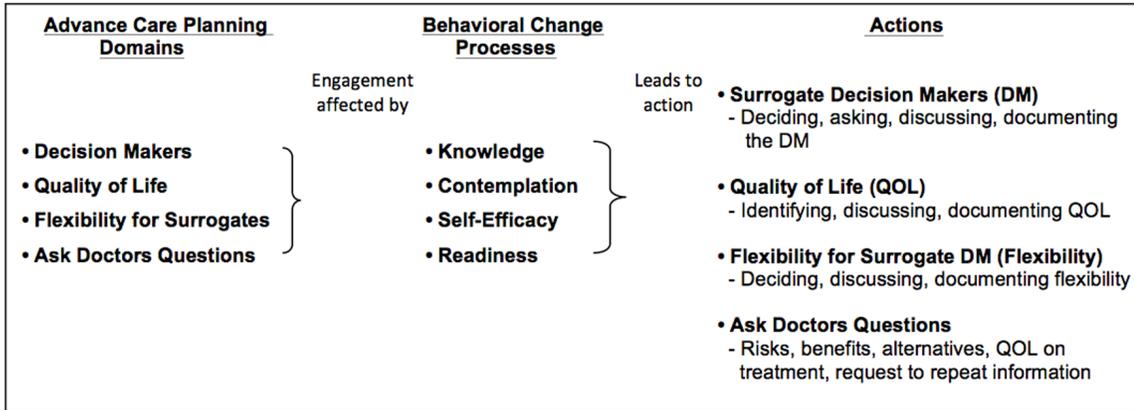
Figure 2: *Algorithm for Living Will Completion, Showing Different Stages of Change*



Through their research, Sudore and colleagues determined that four behavioral change processes affected a person’s engagement in ACP, including the person’s stage of change under the TTM (Fried et al., 2010; Sudore & Fried, 2010; Sudore et al., 2013). These processes include knowledge, contemplation, self-efficacy, and readiness (Sudore et al., 2013). The processes are further discussed in Chapter 2. The four behavioral change processes influence each of the four ACP domains of decision making, quality of life, flexibility for surrogates, and asking questions and move people along the stages of change from the TTM model (Sudore et al., 2013). Figure 3 shows the relationship between the behavioral change processes and the actions people take within the ACP domains that are part of the health behavior change. Engagement in each of the four identified domains is affected by a person’s knowledge of the behavior, contemplation of the behavior, inherent self-efficacy, and readiness to engage in the behavior. The end result in each domain is a series of actions that include choosing a surrogate and asking them, discussing goals of care and values with the surrogate and the provider, and asking providers questions about treatment and alternatives. Throughout this series of processes

and actions, the healthcare provider guides the patient by supplying information about health status, disease trajectory, and available treatment options. As the patient's condition changes, the provider must update the patient on the potential changes to the treatment plan in order to assist the patient in making informed decisions.

Figure 3: *Interaction of ACP Domains, Behavioral Processes, and Actions*



Findings from this research could assist in determining the association between engagement in ACP and various predictor variables, including heart failure stage as determined by the American College of Cardiology Foundation and American Heart Association (ACCF/AHA), heart failure class as determined by the New York Heart Association (NYHA), patient perception of health status, recent hospitalizations, and sociodemographic variables. Understanding which predictor variables affect a person's stage of change will assist in future research to develop interventions based on stage of change, rather than interventions that are very general. If interventions are based on the TTM's stages of change, they may be more successful with patients with heart failure.

The frequency of occurrence of discrete advance care planning behaviors such as appointing a healthcare proxy, discussing healthcare preferences with the proxy and providers, and completing advance directives has not been well described in the heart

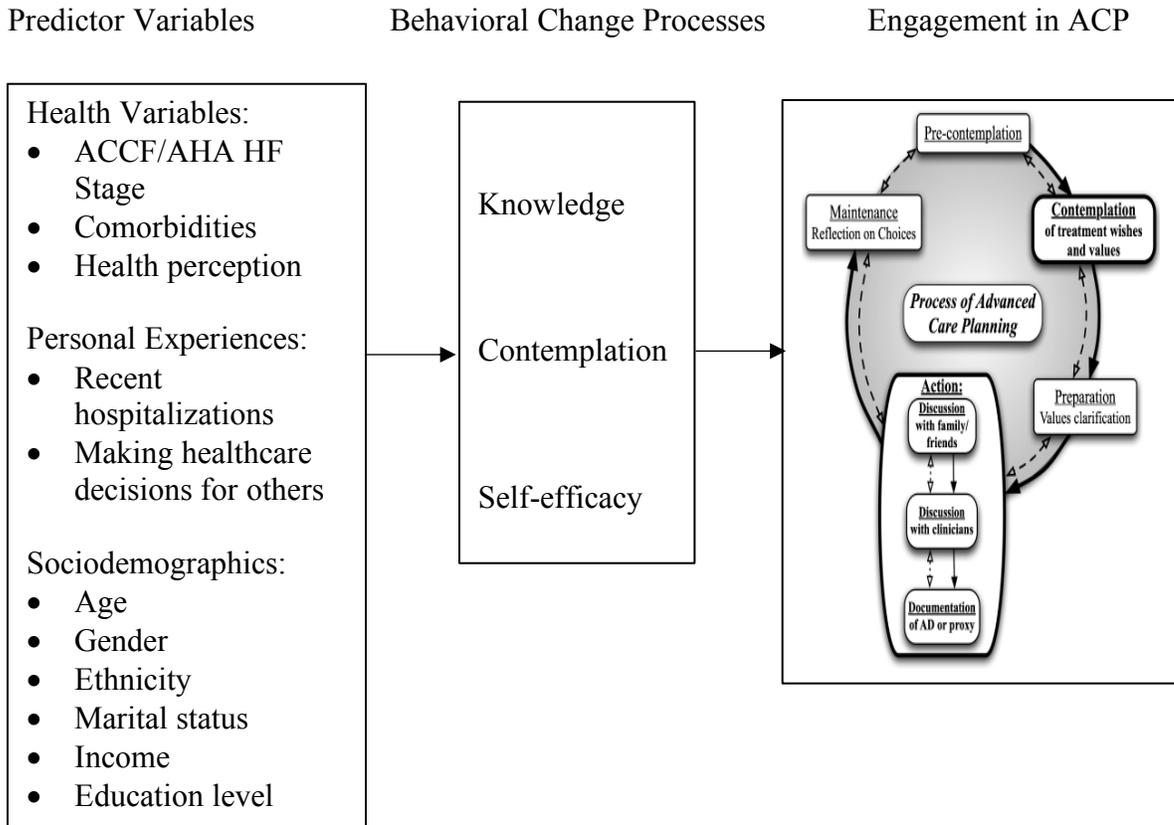
failure population. Percentages of heart failure patients with advance directives range from 12.7% (Butler et al., 2015) to 41% (Dunlay, Swetz, Mueller, & Roger, 2012), but these results do not distinguish between living wills and appointment of surrogates, nor do they include discussion of preferences with providers and proxies. Recently, Yadav et al. (2017) found that 38.2% of adults with chronic illnesses had completed advance directives, as opposed to only 32.7% of healthy adults. When divided into type of advance directive, Yadav noted that 33.4% of all patients had appointed a surrogate decision-maker.

Additionally, no studies to date have been focused on the relationship between heart failure stage or class and engagement in advance care planning. The current study will inform future research by determining how disease stage and other variables impact level of engagement. If relationships between HF stage and engagement in ACP are found, it may guide the development of targeted interventions focused on heart failure stage or class. The goal of these targeted interventions would be to have individuals participate in ACP, which would then increase the ability of healthcare providers to provide care that is consistent with an individual's preferences.

The current research is based upon the TTM model, but the model to be tested adds in certain patient characteristics and experiences that could affect a person's stage of change as related to ACP. These characteristics are potential predictor variables in the model and include health variables such as ACCF/AHA heart failure stage; NYHA heart failure class; comorbidities; perception of health status; personal experiences such as recent hospitalizations and making healthcare decisions for others; and sociodemographic

characteristics such as age, gender, ethnicity, marital status, income, education level, and health literacy. Figure 4 illustrates the model for the currently proposed research.

Figure 4: *Factors Affecting Engagement in ACP*



Research Aims

The specific aims and research questions of the study were:

Specific Aim 1: To describe advance care planning engagement in patients with heart failure.

Research questions for Specific Aim 1 included:

1A. What are the characteristics of patients who are participating in this study of advance care planning?

1B. What percentage of patients in this study report having appointed a surrogate decision-maker for health care decisions?

1C. What percentage of patients in this study report discussions of values and goals of care with surrogate decision-makers?

1D. What percentage of patients in this study report discussions of values and goals of care with healthcare providers?

1E. What percentage of patients in this study report having completed advance directives?

Specific Aim 2: To explore the association between patient engagement in advance care planning and ACCF/AHA heart failure stage; NYHA heart failure class; comorbidity index; patient perception of health status; recent hospitalizations; and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, and religiosity.

Research questions for Specific Aim 2 include:

2A. What is the strength of the association between engagement in advance care planning and ACCF/AHA heart failure stage?

2B. What is the strength of the association between engagement in advance care planning and NYHA heart failure class?

2C. What is the strength of the association between engagement in advance care planning and patient comorbidities?

2D. What is the strength of the association between engagement in advance care planning and patient perception of health status?

2E. What is the strength of the association between engagement in advance care planning and any recent hospitalization?

2F. What is the strength of the association between engagement in advance care planning and making healthcare decisions for others?

2G. What is the strength of the association between engagement in advance care planning and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, religion, and health literacy?

CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Chapter 1 presented the nature of the current study including a statement of the problem, the study purpose, specific aims and hypotheses, the conceptual model, and conceptual and operational definitions. This chapter will provide an overview of heart failure as the disease process of interest; the current scientific evidence regarding ACP, including that related specifically to heart disease; an overview of both Prochaska's Trans-Theoretical Model (TTM) and Sudore's (2017) advance care planning engagement model; and an explanation of the proposed conceptual model.

Overview of Heart Failure

Heart failure is a complex, multifactorial condition that affects over five million adults in the United States. It is characterized by the heart's inability to sustain an output that is sufficient to meet the needs of the body. Heart failure is a contributing factor to over ten percent of all U.S. mortalities (Heidenreich et al., 2013; Saour, Smith, & Yancy, 2017). Risk factors for heart failure include family history; hypertension; maladaptive health behaviors such as smoking, sedentary lifestyle, and an atherogenic diet (i.e., high in cholesterol and saturated fats); age; male gender; and cardiac defects, with most patients having several risk factors (Brashers, 2014). Diagnosis is typically prompted by patient-reported symptoms, such as exercise intolerance, fatigue, fluid retention, and shortness of breath (Brashers, 2014). Notable signs will include dependent edema, crackles indicative of pulmonary edema, and jugular venous distention (Hammond et al., 2016). Diagnostic testing such as echocardiography and right-sided cardiac angiograms are used to confirm the suspected diagnosis (Hammond et al., 2016).

Classes and Stages

There are two approaches to categorizing HF. The American College of Cardiology Foundation and American Heart Association (ACCF/AHA) describe stages of HF that focus on the development and progression of the disease and can be used to describe both individuals and populations (Yancy et al., 2013). Staging is done by the healthcare provider and includes objective consideration of structural changes in the heart and ejection fraction (EF). Possible structural changes include hypertrophy or dilation of heart chambers and valvular dysfunction. EF, the percentage of blood volume ejected from the left ventricle with each contraction, is also examined and contributes to the staging. Measurement of both structural changes and EF can be done through non-invasive testing such as an echocardiogram. Once an individual has progressed to a later stage, that progression is irreversible. Progression along the stages is linked to increased morbidity rates over a 5-year period.

The New York Heart Association (NYHA) describes classes of HF that are based upon patient-reported symptom severity and individual functional capacity (Yancy et al., 2013). It is a more subjective assessment and can change frequently over short periods of time, with patients fluctuating between classes. However, the NYHA is still widely used by cardiology providers in both clinical practice and research and for the determination of eligibility of healthcare services such as visiting nurses, supplemental oxygen, and cardiac rehabilitation because it is an independent predictor of mortality (Yancy et al., 2013). A comparison of the two classifications is shown in Table 2.

Table 2: *Comparison of Stages and Classes of Heart Failure*

ACCF/AHA Stages of Heart Failure		NYHA Functional Classification	
A	At high risk for HF but without structural heart disease or symptoms of HF	None	
B	Structural heart disease but without signs or symptoms of HF	1	No limitation of physical activity. Ordinary physical activity does not cause symptoms of HF.
C	Structural heart disease with prior or current symptoms of heart failure	1	No limitation of physical activity. Ordinary physical activity does not cause symptoms of HF.
		2	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in symptoms of HF.
		3	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes symptoms of HF.
D	Refractory HF requiring specialized interventions	4	Unable to carry on any physical activity without symptoms of HF, or symptoms of HF at rest.

Key: ACCF = American College of Cardiology Foundation; AHA = American Heart Association; HF = heart failure; NYHA = New York Heart Association.

Patients diagnosed with heart failure are staged based on the ACCF/AHA criteria (A, B, C, or D). Treatment options are individualized based on the stage, the ejection fraction, and any comorbidities (Hammond et al., 2016; Yancy et al., 2013). For patients in Stage A, treatment is focused on recognizing and treating precipitating conditions such as hypertension and hyperlipidemia, and controlling comorbid conditions such as diabetes, obesity, and tobacco cessation (Yancy et al., 2013). Diagnosis of Stage A is based on these pre-conditions because there are no overt signs or symptoms. Once patients have progressed to Stage B, pharmacotherapy is used to prevent symptoms and further structural deterioration; management of the comorbid conditions also continues

(Yancy et al., 2013). Patients in this stage are still often undiagnosed, because they have few or no functional limitations. Stage C patients require more intense pharmacotherapy; implanted devices such as biventricular pacemakers and automatic internal cardiac defibrillators are also likely indicated at this time (Saour, Smith, & Yancy, 2017; Yancy et al., 2013). Finally, end-stage patients fall into Stage D. At this point in the disease process, comorbid conditions, age, and patient preferences will determine whether more intensive treatments are selected; such treatments range from intravenous infusions of supportive medications to left ventricular assistive devices to cardiac transplantation (Hammond et al, 2016; Yancy et al., 2013). NYHA class is also used to determine the effectiveness of treatment because the classifications require consideration of both patient symptoms and functional limitations (Yancy et al., 2013).

Trajectory of Heart Failure

Heart failure is an unpredictable condition, with approximately 50 percent of those diagnosed dying within five years (Saour, Smith, & Yancy, 2017). The other 50 percent experience a slow but steady decline with periods of stability and exacerbations. Prediction of a patient's progression through the stages of the disease involves consideration of multiple factors, including: functional tests such as oxygen consumption; serum markers such as natriuretic peptide levels and creatinine levels; response to medications and other interventions; and comorbid conditions, making it difficult for providers to estimate impending mortality (Kheirbek et al., 2013). These exacerbations often require repeated hospitalizations and, with later stages, often bring patients to life-or-death situations. Because of the availability of extensive treatment options, patients are usually stabilized after these exacerbations, making long-term prognoses difficult.

Additionally, many patients' comorbid conditions such as diabetes mellitus and chronic kidney disease will hasten progression along the heart failure trajectory (Ahluwalia et al., 2012).

Costs of Heart Failure

Heart failure is one of the most expensive chronic conditions in the U.S., with 2012 direct costs exceeding \$21 billion, and 2030 direct costs estimated to increase to \$53 billion. Adding in the indirect costs, such as sick days and loss of productivity, brings the total estimated cost to \$70 billion in 2030 (Heidenreich et al., 2013). This estimate assumes that the prevalence of heart failure remains the same and that the increase in technological costs remains stable. Twenty-five percent of Medicare spending on heart failure is spent during the last year of life, and these costs are increasing because of the increased numbers of patients with some degree of heart failure and increases in technological advances (Chen-Scarabelli et al., 2015).

The Joint Commission and Other Recommendations

Many regulatory bodies issue recommendations for treatment of heart failure, including The Joint Commission (TJC), the AHA, and the ACCF. These treatment recommendations include not only medications and devices, but also recommendations for social services, counseling, and advance care planning. These recommendations are published in the form of reportable performance measures or official treatment guidelines.

TJC issues standardized reportable performance measures for facilities to obtain Advanced Certification in Heart Failure (ACHF), developed to emphasize transition of care for the heart failure patient. Facilities are required to collect data on six measures in

order to obtain and maintain the ACHF from TJC, including ACHF-04, “Discussion of Advance Directives/Advance Care Planning;” and ACHF-05 “Advance Directive Executed” (TJC, 2015). Discussion of advance directives/advance care planning requires that there be documentation of at least one discussion of either advance directives or advance care planning in the medical record (TJC, 2015). The execution requirement, ACHF-05, requires that there be documentation of the execution of an advance directive in the medical record unless the patient was discharged to hospice or is designated as receiving only comfort care measures (TJC, 2015).

The AHA also issues a set of guidelines, “Get with the Guidelines” (GWTG) that are designed to ensure evidence-based care for patients with heart failure. GWTG addresses a series of evidence-based care guidelines that were formerly part of TJC’s Core Measures for Congestive Heart Failure, including certain medications to be prescribed, rehabilitation consultations, and the presence of an advance care plan or surrogate decision-maker appointment in the medical record (AHA, 2013). Beginning in 2019, the AHA and TJC will collaborate for all heart failure certification to ensure standardized, evidence-based care for all patients diagnosed with heart failure; this certification will combine the data collection described above and participation in the GWTG program (TJC, 2018).

Finally, the AHA, the ACCF, and the Heart Failure Society of America (HFSA), issue guidelines for the management of heart failure. The 2016 and 2017 guidelines made no changes to the 2013 guideline on care coordination, which includes a recommendation that cardiologists, advanced practice nurses, and other members of the healthcare team should be familiar with advance care planning in order to “enhance the

overall quality of decision making and integrated care for these patients, regardless of the . . . therapy selected” (Yancy et al., 2013).

Advance Care Planning

When individuals are able to communicate their goals of care with their healthcare providers and family, treatment can be formulated based upon those goals. If individuals are unable to communicate their goals, however, then families and providers are often called upon to make decisions without sufficient knowledge of the patient’s goals of care. Advance care planning (ACP) is a process of planning future healthcare in order to ensure that patients’ preferences are followed in the event that they are unable to make their own decisions (Sudore et al., 2017b; Sudore et al., 2013).

Advance Care Planning Documentation Tools

There are a variety of tools used to document a person’s preferences for future healthcare elicited through an ACP discussion. These tools range from provider orders that are initiated at each hospital visit to enduring documents that reflect the person’s preferences of care in particular situations, such as living wills and documentation of healthcare proxies.

Advance directives. Living wills and healthcare proxies (also known as healthcare powers of attorney) are the most common forms of advance directives relevant for care at the end of life. Living wills are documents that list certain medical situations and the patients’ preferences about what to do in those situations; Living wills typically address situations such as persistent comas, cardiac arrest, and respiratory arrest (Levi & Green, 2010). Healthcare proxies, sometimes referred to as surrogate decision-makers, are persons appointed by a patient to make healthcare decisions in the event that a patient

is unable to do so (Levi & Green, 2010). The effects of advance directives, including benefits and barriers, will be discussed in a later section.

Code status orders. Code status orders address whether or not a person wants to be resuscitated upon cardiac or respiratory arrest and are one way to document a person's preferences for healthcare (Yuen, Reid, & Fetters, 2011). The most common of these are do-not-resuscitate (DNR or DNAR) orders, which mandate that the patient will not receive medications, cardiopulmonary resuscitation, or intubation. Patients may dictate certain alterations to them, including requesting all resuscitation measure other than intubation (DNI, or do-not-intubate order). These changes are based upon patient preferences after discussion with a healthcare provider. Many studies have shown the effects of a DNR order. These studies focus on patients not only in hospitals, but also nursing homes, and overall show a decrease in the administration of life-sustaining treatment, not limited to cardiopulmonary resuscitation. Studies have revealed decreases in the use of mechanical ventilation, inotropic and vasopressive medications, and dialysis (Chang et al., 2010; Huang et al., 2010; Sinuff et al., 2004). Patients from nursing homes with various diagnoses, including cognitive impairment, acute respiratory illnesses, and other chronic diseases, have lower rates of hospitalization when they have a DNR order on file (Gozalo et al., 2011; Miller, Gozalo, & Mor, 2001; Rector et al., 2005; Teno et al., 2011; Zheng et al., 2011; Zweig et al., 2004).

Physician Orders for Life-Sustaining Treatment (POLST). The POLST is a relatively new tool for documenting patient preferences for care and address situations where a patient has determined he or she does not want life-sustaining treatment. Designed for those with serious illnesses, POLST address similar areas to those

addressed by a living will, including preferences for CPR and artificial nutrition, but also address whether or not a patient wants hospitalization or antibiotics in given situations (Hickman et al., 2010). These orders, unlike facility-specific DNR orders, follow a person from home to all healthcare facilities, including hospitals and nursing homes. The orders are outcome-neutral, meaning that they can reflect a person's preference either to avoid life-sustaining treatment or to accept it. They are also true medical orders, unlike a living will, and thus do not require additional interpretation (Hickman et al., 2010).

Since its inception, POLST has been shown to improve both documentation of patient wishes and provision of care congruent with these preferences (Hickman, Keevern, & Hammes, 2015). POLST has been shown to be successful in a variety of healthcare facilities, including nursing homes and hospices (Hickman et al., 2010; Meyers et al., 2004). Some researchers found, however, that the forms are sometimes incomplete and even contradictory, leading to confusion as to a person's healthcare preferences (Clemency et al., 2017).

The Origin of Advance Care Planning

Advance directives were the original legal documents that people used to express their wishes regarding certain treatment decisions. The legal support for advance directives stemmed originally from bills introduced in Florida and California with the support of the Euthanasia Society of America (Sabatino, 2010). Although the bills were defeated in both states for several years, California passed the first law to sanction living wills in 1976 (Sabatino, 2010). Over the next fifteen years, states slowly began passing laws allowing advance directives, with all 50 states allowing some form of advance directive by 1992.

The first major court case to uphold the concept of advance directives was *In re Quinlan* (NJ 1976), where Karen Quinlan, a 21-year-old woman in a persistent vegetative state was legally permitted to be removed from a ventilator based on her parents' wishes. Although Quinlan had no documentation about her wishes, the concepts of patient autonomy to refuse treatment and surrogate decision-makers for those without decisional capacity arose from this case.

The United States Supreme Court upheld the right to refuse medical treatment in *Cruzan v. Director, Missouri Department of Health* (1990), and also set the stage for families and other loved ones to produce evidence in the absence of an advance directive that would allow the right to die in certain situations. Like Karen Quinlan, Nancy Cruzan was in a persistent vegetative state. Her family and friends provided testimony that she would not want to live in such a state if she had the capacity to make the choice herself. Eventually, her feeding tube was removed, life-supporting care was withdrawn, and she died.

Based on this case, the federal government established the legality of advance directives in 1990 with the passage of the Patient Self-Determination Act (PSDA), which guarantees patients the right to legally designate a surrogate decision-maker for healthcare decisions in the event of patient incapacity (42 U.S.C. §1395cc, §1396a). Aimed at ensuring patient autonomy in healthcare decisions and in the creation of advance directives, the Act requires healthcare facilities reimbursed by Medicare to inform patients of their rights to: (1) make their own healthcare decisions; (2) accept or refuse medical treatment; and (3) create advance directives. The Act does not require that a healthcare provider initiate a discussion about advance directives, nor does it

require that the facility provide extensive education about advance directives and their goals. It also does not include provisions for reimbursement for such discussions or education.

The goal of advance directives under the PSDA was to preserve individuals' autonomy to make medical decisions when they can no longer speak for themselves (Fagerlin & Schneider, 2004). Ideally, this would have resulted in increased advance care planning, resulting in medical treatment and end-of-life care that was more congruent with patient wishes. Since the enactment of this law, however, it is unclear whether the percentage of those with advance directives has increased, with one study finding that there has been a significant increase (Silveira, Kim, & Langa, 2010), but others finding little to no change in the number of people with advance directives (Rao, Anderson, Lin, & Laux, 2014; Fagerlin & Schneider, 2004). Critics of advance directives note that several factors may impact the lack of advance directives. First, people are unable to accurately predict their wishes for future medical care because of an inability to understand its potential complexities. While this may be due to a lower health literacy, it may also be due to the information provided by the physician in conversations about advance directives, or may be due to a patient completing the documents without physician input at all (Fagerlin & Schneider, 2004). Conversations that do occur tend to be very short, and tend to deal with potential sequelae of an illness in very general terms that prove difficult to use to guide healthcare (Teno et al., 2007; Tulskey, Fischer, Rose, & Arnold, 1998). This lack of discussion could be from a lack of time on the provider's part to thoroughly explain all of the possibilities (Levi & Green, 2010). People may also underestimate the impact debility will have on their lives in the future, and thus may be

unable to predict how they would make certain decisions (Fagerlin & Schneider, 2004; Levi & Green, 2010). Once living wills are completed, people struggle to even understand what they have placed into writing due to the language used (Fagerlin & Schneider, 2004).

Other reasons that advance directives are not as effective as desired include the difficulty of putting complex situations into writing and the translation of the directive to actual medical situations. Living wills typically include a list of situations and treatments for a patient to indicate they want or are refusing. Aside from the problems noted regarding understanding terminology and medical complexities, living wills often limit their instructions to general terms (Fagerlin & Schneider, 2004; Olick, 2012). Thus, an example may be a question that asks a patient whether or not he wants to have mechanical ventilation. In the actual situation, there will be a variety of factors that impact whether or not a patient may have elected for or against mechanical ventilation, including the reason, estimated time on a ventilator and the possibility of recovery. The healthcare team and the patient's appointed or default surrogate decision-maker must then extrapolate from the brief information found on the form plus whatever knowledge they have extraneous to the form (Fagerlin & Schneider, 2004).

Finally, there is evidence suggesting that advance directives have little effect on the actual decisions made on behalf of patients. The SUPPORT study, a multi-center, five-year study, found that advance directives "failed to improve care or patient outcomes" (Connors et al., 1995). Several years later, Prendergast noted that while healthcare providers document the presence of advance directives more often, the percentage of patients with them had not increased (2001). Additionally, those with

advance directives often received care that conflicted with their stated directives (Jezewski et al., 2005; Scherer et al., 2006). Even in the presence of formally executed advance directives, healthcare providers will often follow conflicting preferences of family members at the bedside (Rolnick, Asch, & Halpern, 2017).

The Shift to Advance Care Planning as a Process

In response to the failure of advance directives, healthcare providers began conceptualizing and promoting the importance of advance care planning as a process rather than a document. This process includes selection of a surrogate decision-maker (SDM); discussions with family members, other loved ones, and healthcare providers about values and goals of care; and the completion of ADs (Piemonte and Hermer, 2013; Rogne & McCune, 2014; Sudore et al., 2013; Sudore et al., 2017). Although it will involve the discussion of end-of-life (EOL) care, ACP has come to be understood as being more than just EOL planning, and in fact should be initiated and revisited with the progression of any chronic disease (Sudore et al., 2013). The newest consensus definition of ACP notes that it is for all adults “at any age or stage of health” and should include discussion of diseases and prognosis, values, life goals, and preferences about healthcare (Sudore et al., 2017b). ACP is not just for older adults; it is “about planning for the ‘what ifs’ that may occur across the entire lifespan” (Benson & Aldrich, 2012, p. 2).

Researchers in ACP encourage people and providers to begin ACP early in the disease process and continue with both disease progression and advances in treatment (Rao et al., 2014; Sudore et al., 2013; Sudore et al., 2017b). ACP includes not only end-of-life planning, but also extensive discussion about patient goals for the future (Sudore

et al., 2013; Sudore et al., 2017a; Sudore et al., 2017b). Healthcare providers are encouraged to extensively discuss the disease process, prognosis, and potential outcomes with patients, including their values and wishes regarding invasive treatments, life-sustaining and supportive care, palliative care, and end-of-life preferences (Ahluwalia et al., 2013; IOM, 2014; Sudore et al., 2017b; Weinstock & Johnson, 2011).

Recently, calls for advance care planning picked up momentum with the publication of the Institute of Medicine's report *Dying in America* (IOM, 2014). The IOM emphasized the need for person-centered care at the end of life, focusing on the use of palliative care and advance care planning. The committee noted that advance care planning, done early in the disease process, will "reduce confusion and guilt among family members forced to make decisions about care" (IOM, 2014, p. S1) Included in the IOM's recommendations was the need to "develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence based" (IOM, 2014, p. S10, 3-56).

Despite the recognition that advance care planning should be expanded from end-of-life planning to an ongoing process, two-thirds of U.S. adults have never participated in the ACP process, even today (Benson & Aldrich, 2012; Rao et al., 2014; Yadav et al., 2017). While the rates of completion of ADs alone do increase with age, the rates of ACP discussions with healthcare providers remain low (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014).

Effects of Advance Care Planning

Advance directive completion. Advance care planning has been shown to have many benefits, both psychological and financial. Although the usefulness of advance

directives is debated, advance care planning does increase the rates of completion of both living wills and health care powers of attorney (Ahluwalia, Levin, Lorenz, & Gordon, 2013; Evangelista et al., 2012; Heffner & Barbieri, 2001; Schellinger, Sidebottom, & Briggs, 2011; Silveira, Kim, & Langa, 2010). In a quasi-experimental, one-group pre- and post-test study, Evangelista and colleagues (2012) found that the rates of AD completion increased from 28% to 47% three months after an intervention focused on health perceptions, knowledge of ADs, discussion with family and providers, and completion of ADs. Heffner and Barbieri (2001) focused on patients in multiple cardiac rehabilitation programs and found that 49% of those in the intervention group had completed living wills and/or DPAHCs, compared to only 38% in the control group. Schellinger, Sidebottom, and Briggs (2011) evaluated the Respecting Choices® program and found that 94.3% of those who had participated in the program had completed ADs, as compared to only 24.8% of those who had received only the usual care.

Care congruent with patient wishes. ACP also improves the healthcare team's ability to respect and implement an individual's goals of healthcare, especially during times of decisional incapacity, such as with serious illness exacerbations or at the end of life (Silveira et al., 2010). This may be partially accomplished with a living will, if it speaks to the specific situation. However, ACP goes far beyond the dictates of the living will; conversations about goals of care between the patient, family and surrogates, and healthcare providers will allow decisions made to be more reflective of the patient's wishes. Detering and colleagues (2010) used a program similar to the Respecting Choices® intervention to encourage ACP, and then later measured whether the patients' end-of-life care had coincided with their wishes by contacting families after death. This

was done by comparing documentation of patient wishes in the medical record and family statements to the actual care provided prior to death. Results showed that those patients who had engaged in the ACP intervention were significantly more likely (86%) to have their end-of-life wishes known and respected than those without the ACP intervention (30%) (Detering et al., 2010).

Other researchers have looked at nursing home residents and congruence of care; those residents who regularly discussed advance care planning were significantly more likely to have their wishes followed than those who did not (Morrison et al., 2005). The study intervention involved routinely raising the topic of ACP in patient care discussions. Only 5% of patients with ACP had treatments that violated their wishes (one was hospitalized and one received intravenous antibiotics), where 18% of those without ACP had some form of treatment that violated their wishes for treatment (Morrison et al., 2005). One similar study, however, did not show a statistically significant difference in the congruence of end-of-life care received after an ACP intervention for heart failure and renal failure patients (Kirchoff et al., 2012). The researchers noted that for this particular study, patients who received the ACP intervention continued to make their own decisions until very near end of life, rather than the decisions being made by a surrogate decision-maker identified during the intervention. They speculated that this may have been the reason there was no statistically significant difference between those with and without the intervention.

Satisfaction with care. Along with having their preferences followed, patients and families who received an ACP intervention also report increased satisfaction with healthcare. One study found that both discharged patients themselves and families of

deceased patients were significantly more likely to be highly satisfied with the hospital care they had received when ACP had been facilitated by use of an intervention (Detering et al., 2010). Veterans Affairs medical centers also saw the same increase with patient satisfaction when advance care planning was undertaken (Engelhardt et al., 2006). Other studies have focused on primary care and on specialty care and have also found that advance care planning increases patient satisfaction in those arenas as well (Kass-Bartelmes & Hughes, 2009; Tierney et al., 2001). The same increase in patient satisfaction has been seen in a variety of patient diagnoses, including cancer (Jones et al., 2011), dementia (Sampson, 2011), and HIV (Lyon et al., 2009).

Other studies have shown no significant difference in family/surrogate satisfaction with patient care. Volicer, Hurley, and Blasi (2003) examined patients with dementia and compared those with and without advance care planning. No statistically significant difference was found between the two populations of patients as to satisfaction with care. Similarly, Pautex, Herrmann, and Zulian (2008) examined patients in palliative care for differences associated with the presence of advance directives. No statistically significant differences were found between the two groups of patients as to satisfaction with the care they received. This finding has also been seen in patients with HIV; one study showed a decrease in patient satisfaction after an ACP intervention, but this decrease was not statistically significant (Ho, Thiel, Rubin, & Singer, 2000).

Improvements in end-of-life care. Improved end-of-life care is another benefit of advance care planning. Multiple studies have shown an improvement in this area, including decreases in unwanted hospitalizations, decreases in the use of mechanical ventilation or tube feeding, and increases in numbers of deaths at home or in a residence

other than a hospital. Gozalo and colleagues (2011) examined the benefits of advance care planning documentation (including advance directives) in nursing home residents and found that those with such documentation were less likely to be hospitalized in the three months prior to death than those without it. Similar results were shown by researchers studying the unit of admission; patients who had engaged in ACP were less likely to be admitted to a medical intensive care unit for aggressive treatment (Cohen et al., 2012).

ACP has also been shown to decrease the rates of hospitalization for people living in extended care facilities. Gozalo and colleagues (2011) looked at nursing home residents with advanced cognitive and functional impairment and found that those with advance directives had lower rates of hospitalization at the end of life. Similarly, Molloy (2000), Morrison (2005), Caplan (2006), and Levy (2008) found that the use of an advance care planning intervention or improved documentation of advance care planning decreased later hospitalizations among nursing home residents.

A related aspect is length of hospital stay; some studies have shown that ACP decreases both the length of the hospital stay in general, and length of ICU admission specifically, near the end of life. Critically ill cancer patients had shorter ICU stays if they had ACP documented in their records (Wallace et al., 2001). Volicer (2003) found similar results, with shorter hospital stays and increased numbers of deaths in nursing homes as opposed to in hospitals for patients with dementia who had completed ACP prior to death. At least one other study, however, found no difference in the length of hospital stay between those with and those without advance care planning (Levy et al., 2008).

Some research has shown that advance directives alone can impact the quality of a person's end of life (Glavan et al., 2008), but results from several studies show no statistically significant relationship solely between the presence of advance directives and quality of life (Loberiza et al., 2011; Pautex et al., 2008; Vandervoort, 2014; Volicer et al., 2003). However, more comprehensive ACP that includes discussions of preferences for care with both family and providers has been shown to produce improved quality of life, including both physical and psychological factors (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Chan & Pang, 2010; Fried et al., 2009; Schamp & Tenkku, 2006; Wright, Zhang, & Ray, 2008). Conflicting research, however, has shown no correlation between improved quality of life and advance care planning in patients with cancer (Jones et al., 2011; Lyon et al., 2014).

Benefits to surrogates. ACP has also been shown to benefit people other than the patient. Surrogates and family members often struggle with making healthcare decisions about patients, leading to psychological distress and even post-traumatic stress disorder (Kross et al., 2011). This decisional conflict can lead to making treatment decisions that are not aligned with the patient's preferences (Barnato et al., 2007; Cosgriff et al., 2007; Danis et al., 1996). It can then lead to regret on the part of the surrogate and lower quality of life on the part of the patient (Cai et al., 2015; Tejwani et al., 2013). Advance care planning, when it includes discussions with surrogates about goals of care, decreases surrogate and family stress, including allowing them to have more confidence in their decisions (Chiarchiaro, Buddadhumaruk, Arnold, & White, 2015; Detering et al., 2010).

Financial effects. Financially, ACP has been shown to decrease the use of aggressive medical treatment at the end of life, including admission to intensive care units (Ache et al., 2014; Bischoff et al., 2013; Wright et al., 2008; You, Fowler, & Heyland, 2014). It is also correlated with increased use of hospice care, resulting in more deaths in hospice than in hospitals, because of ADs that specify comfort care at end of life instead of aggressive treatments (Wright et al., 2008).

Barriers to Advance Care Planning

Data from multiple studies show barriers to advance care planning on the parts of both the healthcare provider and the patient. Commonly reported patient barriers on the include reluctance to ask questions, a fear of upsetting family members, a desire to leave any decision-making up to family, a perception that advance care planning does not apply to them, and misunderstanding the purpose of ACP. Commonly reported provider barriers include not wanting patients to lose hope, not being experienced enough to discuss ACP, and waiting until patients ask to discuss ACP. These barriers will be discussed in more detail in the next section.

Patient barriers. Patients' reluctance to ask questions about their disease processes is a primary barrier to engaging in ACP (Caldwell, Arthur, & Demers, 2007; Harding et al., 2008; Strachan et al., 2009). This reluctance can stem from a fear that they will place the provider in an uncomfortable position in having to discuss EOL care or that the provider will not be ready to have such a discussion (Caldwell, Arthur, & Demers, 2007). Some patients also fear that they would be labeled as "difficult" patients if they question their providers about prognosis and advance planning (Boyd et al., 2004). Patients also report concerns that the provider will not give them truthful information and

thus refrain from initiating the conversation (Harding et al., 2008; Strachan et al., 2009). Many patients also believe that physicians do not have the time to talk to them about prognosis and advance planning (Aldred, Gott, & Gariballa, 2005).

Patients also report that they believe the provider should initiate advance care planning, which is thus a barrier to patient initiation of ACP (Caldwell, Arthur, & Demers, 2007; Rodriguez et al., 2008b). Many patients think that the provider will initiate such discussions when it is appropriate, i.e., that the disease is terminal (Caldwell, Arthur, & Demers, 2007; Rodriguez et al., 2008a). Lack of initiation on the part of the provider has led patients to believe that ACP is not yet needed (McCormick, 2009).

Patients may not initiate discussions about prognosis and advance care planning because of anxiety or a desire to focus only on the positive (Agard, Hermeren, & Herlitz, 2004; Barnes et al., 2006; Boyd, Murray, Kendall, Worth, Benton, & Clausen, 2004; Horne & Payne, 2004). This may be a coping strategy for some patients (Heffner, 2011). Many patients report not asking for prognostic information because they did not want to lose hope, but also because they feel it is unnecessary as they cannot change it (Agard, Hermeren, & Herlitz, 2004). Other patients may be in a state of denial about the seriousness of their disease, and thus either do not initiate ACP or refuse to discuss it if initiated by the provider (Gardiner et al., 2009).

Crain (1996) studied frail homebound elderly and found that one of the most common reasons for failure to complete advance directives was that study participants were afraid that it would upset their family members. Schickedanz et al. (2009) studied 143 people over age 50 from a general medicine clinic and found that 43% of them did

not participate in advance care planning because of not wanting to worry or burden their families.

Finally, there are some cultural barriers to engaging in ACP. Some people fail to engage in ACP because of a desire to leave decision-making up to their families. Studies of decision-making of African-Americans have shown that many prefer to allow their family members to make future healthcare decisions for them (Daaleman, Emmett, Dobbs, & Williams, 2008). Phipps (2003) hypothesized that this may be because they feel that family members already know their wishes, and thus there is no need for advance directives. Other studies have revealed data similar to this, with Wagner (2003) noted that living wills were less likely to be completed by African-Americans than Caucasians, and Guo (2010) noting that those of Hispanic or Latino origin were less likely to have both advance directives and DNR orders when afflicted with end-stage cancer.

Cultural differences between different ethnicities may also be related to religion. In African-Americans, religious values, rather than healthcare provider recommendations, are often the guiding force for decision-making for ACP (Johnson, Elbert-Avila, & Tulsky, 2005). End-of-life choices are also affected by religiosity and culture, as religious beliefs tended to be different between different ethnicities in one study (Bullock, 2011). Religion and ethnicity as factors affecting engagement in ACP are also discussed later in this chapter.

Provider barriers. Providers also encounter barriers to initiating ACP conversations, most notably reporting a lack of confidence in their communication skills (Harding et al., 2008; Selman et al., 2007). In one qualitative study, cardiologists' EOL

communication skills were compared to those of oncologists, and cardiologists' skills were found to be lacking (Selman, 2007). Patients recognize this deficiency in communication skills, noting that EOL communication from providers was "poor" or nonexistent (Horne & Payne, 2004; Rodriguez et al., 2008a). Other patients find that provider communication is poor not only when related to advance planning and prognosis, but also about daily care activities (Boyd et al., 2004; Gerlich, Klindtworth, Oster, Pfisterer, Hager, & Schneider, 2012).

Physicians report that they do not want to remove all hope and do not want to cause any psychological or emotional distress in their patients by initiating EOL conversations (Harding et al., 2008). Because of this, they then use less severe words than "terminal" or "fatal," resulting in patient misconceptions about prognosis (Ahluwalia et al., 2013).

Advance Care Planning in Heart Failure

It is difficult for physicians to accurately identify when patients with heart failure are approaching end of life because heart failure has an unpredictable trajectory, with frequent relapses and improvements (Garland, Bruce, & Stajduhar, 2013). Advance care planning conversations therefore cannot be delayed until death is imminent.

Additionally, because of the wide variety of treatment options available, including both non-invasive treatments such as oral medications and invasive therapies such as pacemakers, continuous intravenous medications, and even ventricular assistive devices, the decisions to be made become increasingly complex as the disease progresses (Garland, Bruce, & Stajduhar, 2013).

Despite the national focus on advance care planning and the desires of the patients, many studies of patients with heart failure show that the majority of them report no experience participating in any type of advance care planning, including end-of-life planning, with their healthcare providers (Barclay et al., 2011; Gott et al., 2008; Momen & Barclay, 2011; Rodriguez et al., 2008; Strachan et al., 2009). Many of those who did discuss end-of-life care reported only discussions about resuscitation and completion of legal paperwork rather than in-depth examinations about goals for future care (Barclay et al., 2011). The timing of such conversations is often at the very end of life, when the family is called upon to make decisions, or during times of clinical crisis, when the patient is unable to focus on anything but physical symptoms (Ahluwalia et al., 2013). This lack of ACP often results in the neglect of consideration of patient values concerning treatment and contributes to stress to SDMs as previously discussed.

Conceptual Model

Trans-Theoretical Model

The Trans-Theoretical Model (TTM) was first proposed as a way to understand both the stages of behavior change and the processes related to change when individuals were trying to overcome addictive behaviors such as smoking (Prochaska, DiClemente & Norcross, 1992). The TTM involves multiple actions and adaptations that occur over time. The stages of changes describe a person's readiness to act on a new behavior; a person may cycle through the stages in a "spiral" or revert back to an earlier stage at any time (Prochaska, DiClemente & Norcross, 1992). The five stages of change are: (1) precontemplation; (2) contemplation; (3) preparation; (4) action; and (5) maintenance (Prochaska & Velicer, 1997). Precontemplation is the stage in which a person has no

intention of changing behavior and may even be unaware of the need for a change. In contemplation, a person is aware that there is a need to change, but has no commitment to take action. Preparation involves a person's intention to take action in the near future. Action is the stage in which a person actually modifies behaviors, experiences and/or environments. Finally, maintenance involves stabilization of the new behavior over a period of time. A sixth stage, termination, is sometimes added; this stage indicates that there is no risk of returning to the old behavior. These stages are not necessarily always linear; many individuals will regress and progress through the stages based on motivation and self-efficacy or lack thereof (Whitelaw et al., 2000). Interventions based on the TTM have been shown to be effective in a variety of health behaviors including smoking cessation, regular mammography screening, medication adherence, and improving dietary habits (Johnson et al., 2006; Jones et al., 2003; Krebs, Prochaska, & Rossi, 2010; Prochaska et al., 2005). Interventions based on the TTM have been successful largely because they are specifically designed to target individuals at certain stages of change (Fried et al., 2016).

Model of Engagement in Advance Care Planning

The current research is based upon the TTM and adds in certain patient characteristics and experiences that could affect a person's stage of change as related to ACP. These characteristics are considered potential predictor variables in the model and include health variables such as ACCF/AHA heart failure stage, comorbidities, and perception of health status, personal experiences such as recent hospitalizations and making healthcare decisions for others, and sociodemographic characteristics such as age,

gender, ethnicity, marital status, income, education level, and health literacy. Figure 4 illustrates the model for the currently proposed research (Chapter 1, page 10).

Health Variables

ACCF/AHA heart failure stage and NYHA heart failure classification. The stages, as previously described, are based upon the progressive nature of heart failure and are a continuum from asymptomatic but at-risk individuals to those with severe physical limitations due to the disease (Oh & Borlaug, 2015). People with heart failure progress through the stages via periodic exacerbations and stable periods, but each exacerbation may lead to death. The mortality rate increases as a person progresses through the stages, as do the chances the person will need urgent medical treatment and intensive care (Allen et al., 2012). In the Model, heart failure stage is hypothesized to be a predictor variable because of its impact not only on patient symptoms, but also on a patient's risk of death within a short period of time. Classes are also on a continuum and, similarly, impact both patient symptoms and risk of death. The association between stage and class was illustrated in Table 2.

Comorbidities. Comorbidities are hypothesized to be a factor that helps to predict engagement in advance care planning. Comorbid conditions are those with which a patient has been diagnosed in addition to heart failure. Common conditions include diabetes, coronary artery disease, renal disease, and chronic obstructive pulmonary disease (COPD). As a patient's number of comorbid conditions increases, the deleterious symptoms increase, as does the risk of mortality (Ahluwalia et al., 2012). Comorbidity has been found to be a factor that affected engagement in ACP in previous studies. Bond et al. (2018) examined medical records in a large-scale study (over 120,000 patients over

a four-year period) involving a multisite rural-suburban facility and found that the patients with documented ACP had higher numbers of comorbid conditions. Having heart failure or chronic obstructive pulmonary disease (COPD) also increased the likelihood of having ACP documentation in their medical records. Hash, Bodnar-Deren, Leventhal, and Leventhal (2016) found that the odds of participating in ACP increased with the presence of comorbid chronic illnesses such as heart disease, diabetes, and cancer.

Patient perception of health status. Patient perception of health status is hypothesized to be a variable that helps to predict engagement in advance care planning. Early testing of the ACPES across healthcare settings showed that patients with higher perceived health status were less likely to be engaged in advance care planning than those with chronic health conditions such as renal failure and cancer (Howard et al., 2016). Additionally, preparatory work by this researcher for the current study demonstrated that patients felt their answers to the ACPES could change given their view of their health that day and the way they currently felt (Catalano, 2016).

Patient Experiences

Recent hospitalizations. Recent hospitalizations (within the previous two years) are hypothesized to affect engagement in ACP. Experience with recent hospitalizations is important because patients are asked about the presence of any advance directives when admitted to a facility, potentially triggering patient activity regarding advance care planning. Howard et al. (2016) found that patients who were currently hospitalized were more likely to have completed certain ACP actions, including selection of a healthcare proxy and discussion of healthcare preferences with providers.

Making healthcare decisions for others. Making healthcare decisions for others is hypothesized to affect engagement in ACP. Making healthcare decisions for others, as happens when one is a surrogate decision maker, could potentially trigger patient activity regarding advance care planning. This variable was included in the model because knowledge about a health behavior can move a person from precontemplation to contemplation (Zimmerman, Olsen, & Bosworth, 2000). The effect of the experience of serving as a surrogate on one's own ACP has not been well-studied in the literature. Recently, Genewick and colleagues (2018) researched motivating factors for creating ADs, and included a question regarding making end-of-life decisions for others on their survey. Their research focused on whether intrinsic (dignity and personal control) or extrinsic factors (societal and familial influence) were more motivating, and did not separate out the individual variables. However, they did find that extrinsic factors were more motivating for patients older than age 50. Another study examining motivating factors showed that 31% of people who completed advance directives did so after seeing a family member or friend die from a serious illness (van Wijmen, Pasman, Widdershoven, & Onwuteaka-Philipsen, 2014). The study did not examine whether they had themselves made healthcare decisions for the dying person.

Sociodemographic Variables

Age. Age is a factor that has been shown to affect stage of readiness to engage in advance care planning (Fried et al., 2010). Although age was not a factor that influenced readiness to complete an advance directive in one study, it did impact whether or not a person was ready to discuss quality of life with loved ones, surrogate decision makers, and providers (Fried et al., 2010). Those between 65 and 74 years of age were more

likely to be in the action phase of communicating with loved ones about quality of life (Fried et al., 2010). Nursing home residents aged 75 years and older have also been found to be more likely to have advance care plan documentation, including “do not resuscitate” orders, on file (Dobalian, 2006). Older patients are also more likely to have dementia symptoms; however, the presence of dementia may decrease the likelihood of having end-of-life provisions documented (Mitchell, Kiely, & Hamel, 2004). Age continues to be a variable that impacts ACP in recent research. In 2016, Inoue reviewed over 1000 participants’ information about ACP and found multiple sociodemographic variables that increased the likelihood of having been engaged in ACP, including age. Inoue found that the older a person was, the more motivated he or she was to engage in ACP. Studies have also examined the effect of age in different ethnic groups; Boucher (2017) found that young age was a barrier to ACP in people in New York with Puerto Rican and Dominican ancestry.

Gender. Gender is a factor that has been shown to affect stage of readiness to engage in advance care planning (Fried et al., 2010). Although gender was not a factor that influenced readiness to complete an advance directive in one study, it did impact whether or not a person was ready to discuss quality of life with loved ones, surrogate decision makers, and providers (Fried et al., 2010). Men were more likely to be in the action phase than women for communicating with loved ones about quality of life. A recent study found that men are less likely to have engaged in ACP than women (Doyle, 2016). Inoue (2016) found that women were more likely to have been motivated to engage in ACP than men in a review of over 1000 participants. Similarly, Boerner, Carr, and Moorman (2016) found that women were more likely to have engaged in ACP than

men in a study of almost 300 adults aged 55 years and older who were diagnosed with diabetes, cancer, or heart failure.

Ethnicity. Ethnicity is a factor that has been shown to affect the completion of living wills (Fried et al., 2010). Being nonwhite is associated with a lower stage of change than being white; 60% of white study participants were in the action/maintenance phase, indicating that the living will had been completed or was in process. Only 26% of those participants who were nonwhite were in this stage; 41% were still in the precontemplation stage (Fried et al., 2010). Being African-American has also been shown to impact engagement in ACP (Fried et al., 2010; Johnson, Kuchibhatla, & Tulsky, 2008); lower rates of engagement have been theorized to be due to mistrust of the healthcare system (Johnson, Kuchibhatla, & Tulsky, 2008).

In one study, African-Americans were found to be only one-third as likely than Caucasians to have living wills, but Hispanics were just as likely to have them as Caucasians (Degenholtz, Arnold, Meisel, & Lave, 2002). Disparities were also seen in the percentages of “do not resuscitate” orders, even after controlling for health status and other demographic factors such as age, gender, and marital status (Degenholtz, Arnold, Meisel, & Lave, 2002). Later studies found similar results, with both black and Hispanic patients being less likely than white patients to have engaged in ACP (Dobalian, 2006; Smith et al., 2008). These ethnic differences were still present after controlling for clinical and demographic factors (Smith et al., 2008). A recent study found that African-Americans and Latinos are less likely to have engaged in ACP (Doyle, 2016). Elderly, Spanish-speaking Latinos were the least likely to have engaged in ACP (Doyle, 2016).

Marital status. Marital status is a factor that has been shown to affect stage of readiness to engage in advance care planning (Fried et al., 2010). Marital status impacted whether or not a person was ready to discuss quality of life with loved ones, surrogate decision makers, and providers, with married people more likely to be in the action/maintenance phase of this task, and unmarried people more likely to be in the precontemplation phase (Fried et al., 2010). Married couples are also more likely to engage in ACP than those cohabiting, but this may also have been influenced by age, as older participants were more likely to be married than cohabiting (Moorman, Carr, & Boerner, 2014). Higher levels of spousal support also increase the odds of having ACP discussions with a spouse (Boerner, Carr, & Moorman, 2013).

Income. Sufficiency of monthly income may impact engagement in advance care planning. One study found that nursing home residents with Medicaid were less likely to have an advance care plan than those with Medicare or other forms of healthcare payments (Dobalian, 2006). Residents with income less than 400% of the Federal Poverty Level were also less likely to have a living will (Dobalian, 2006). A recent, as yet unpublished study found that people with low annual incomes are less likely to have engaged in ACP (Doyle, 2016).

Education. Education level has been implicated in engagement in advance care planning. Bullock (2011) found that study participants with lower levels of education were less likely to have engaged in advance care planning; however, this may have been biased by other factors, including ethnicity and perceived health status. Limited education among Latino patients was also shown to affect advance care planning and end-of-life preferences, but these differences were eliminated when educational materials

were provided in an appropriate format (video) and at an appropriate level (Volandes, Ariza, Abbo, & Paasche-Orlo, 2008). Doyle (2016) found that people with lower levels of education are less likely to have engaged in ACP.

Religion. Religion has been shown to be a factor affecting advance care planning, with religiosity having a negative correlation with the likelihood of advance care planning (Garrido, Idler, Leventhal, & Carr, 2013). This has been theorized to be due in some part to the influence of fundamentalist religions (Sharp, Carr, & Macdonald, 2012). End-of-life choices are also affected by religiosity and spirituality, but this may also be affected by ethnic differences, as religious beliefs tended to be different between different ethnicities in one study (Bullock, 2011). One recent study indicated that patients who considered themselves atheists were more likely to have completed documents limiting treatment at the end of life than patients who were Catholic or Protestant (Janssen et al., 2016).

Health literacy. Health literacy has been found to be a factor influencing rates of advance care planning, with adults of low health literacy levels being less likely to complete advance directives (Sudore et al., 2007). Changes to the educational materials, including showing videos of certain medical treatments, have been found to eliminate disparities in ACP based on health literacy (Vig, Berg, & Simon, 2012).

Engagement in Advance Care Planning

Recently, Fried and colleagues examined the TTM to determine if it was a valid model to predict engagement in advance care planning (2009). They noted that behavioral change theories were especially appropriate for ACP theories because they included constructs such as perceived susceptibility, self-efficacy, and barriers to change,

and also a temporal component indicating that it was a process rather than a single event (Fried et al., 2009). They conceptualized ACP as a series of health behaviors that require people to go through behavior change (Fried et al., 2009). These behaviors included not only completion of a living will and healthcare proxy, but also communication with both loved ones and providers about the use of life-sustaining treatments and quantity versus quality of life (Fried et al., 2009). The study participants included both community-dwelling older adults and caregivers with experience as surrogate decision-makers. The qualitative study revealed several themes, including a variable readiness to engage and multiple barriers, validating the researchers' theories that it was a process through which people progressed at different rates (Fried et al., 2009). They concluded that interventions to increase rates of ACP should be customized "based on an individualized assessment of a person's readiness to change, barriers to and facilitators of change, and [a person's] use of processes of change" (Fried et al., 2009, p. 1552).

Fried et al. (2010) later conducted an observational study to develop measures to determine stage of change for the component behaviors of the ACP process, and to use these measures to examine sociodemographic and health variables that could impact stages of change. The study participants were recruited from physician offices and community centers and averaged 75 years of age, and were of diverse ethnic origin, marital status, and quality of life (Fried et al., 2010). The results of the study confirmed that the stages varied for each discrete ACP behavior; individuals could be in the action phase for completion of advance directives, but still be in the contemplation phase for discussion with providers and loved ones (Fried et al., 2010). Data showed that the participants were in the lowest stage of change for communication with physicians about

quality of life, with only 7% in either the preparation or action stage (Fried et al., 2010). Communication with physicians about life-sustaining treatment was also in a low stage of change; only 14% of people were in either the preparation or action stage (Fried et al., 2010).

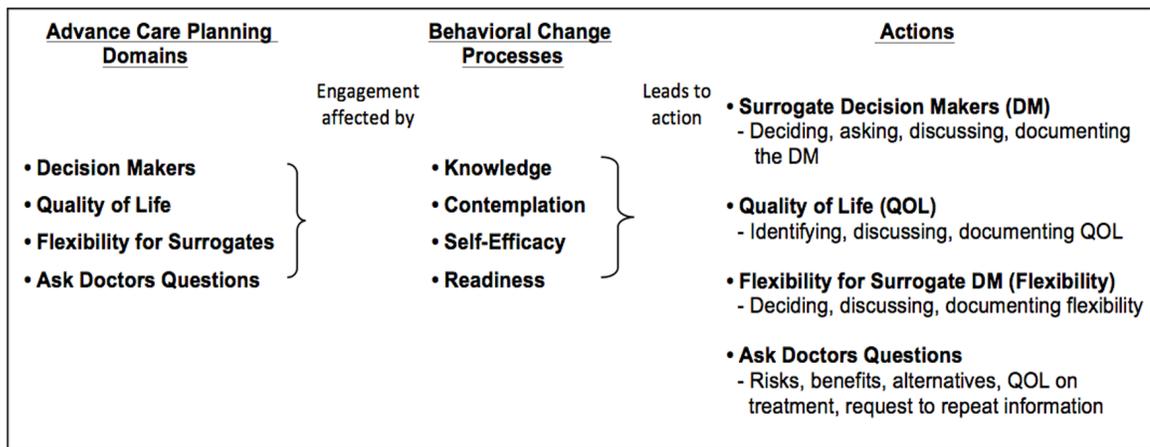
In further work based upon these original studies, Sudore pulled concepts from social cognitive and behavioral change theories and noted that behavior change requires an individual to change several factors related to any particular behavior. These factors include: (1) knowledge of the importance of the behavior; (2) contemplation about the behavior; (3) self-efficacy to perform the behavior; and (4) readiness to perform the behavior (Sudore et al., 2013). Knowledge of the importance of the behavior is dependent upon an awareness that a risk exists (Conner & Norman, 2005). Changing risky behaviors such as smoking, for example, require knowledge that smoking is harmful to one's health. Contemplation refers to the phase in which one is thinking about changing a certain behavior, but has not yet taken any steps toward this change (Conner & Norman, 2005; Prochaska & Velicer, 1997). Knowledge of the health threat is a prerequisite to this stage (Conner & Norman, 2005). Self-efficacy refers to believing in one's capability to successfully complete a certain behavior change (Bandura, 1977; Conner & Norman, 2005). Lack of self-efficacy will typically stall a person in either the contemplation or preparation stage of the TTM (Sutton, 2005). Finally, the concept of readiness indicates that a person is ready to change with regard to a particular behavior (Abraham & Sheeran, 2005). Readiness has a temporal factor in that it is not a willingness to change later, but at the present time (Abraham & Sheeran, 2005).

Advance Care Planning Engagement Survey. Based on the previous factors related to behavior change and the TTM stages of change, Sudore and colleagues developed the Advance Care Planning Engagement Survey (ACPES) in order to measure a person's engagement in each discrete behavior within the ACP process (Sudore et al., 2013). The ACPES examines four domains of ACP: decision makers, quality of life, flexibility, and asking questions. The "decision makers" domain includes identification of a surrogate decision maker and informing them and the providers of the responsibility. "Quality of life" refers to the identification of the person's values and goals and communicating them to the surrogate and provider. The "flexibility" domain includes communicating the amount of leeway the surrogate will have in making decisions. Finally, the "asking questions" domain refers to preparedness to ask providers questions in order to make informed care decisions. Each of the four domains includes several specific behaviors based on the TTM: knowledge, contemplation, self-efficacy, and readiness.

The ACPES originally measured both cognitive processes and actions related to each domain, but has since been adapted for brevity. The 31 process measures are related to knowledge, contemplation, self-efficacy, and readiness. For knowledge, the ACPES asks the patients how well-informed they are about the domains of decision makers, flexibility, and asking questions (quality of life was omitted from this behavioral process). For contemplation, the ACPES asks the patients how much they have thought about each of the four domains. Self-efficacy is assessed by asking patients how confident they are that they could perform the ACP behaviors. Finally, readiness is assessed by asking patients how ready they are to perform those same behaviors. Each of

these is measured on a 5-point Likert-type scale. The 18 action measures of the ACPES were specific yes/no questions to determine if a person was in the action stage of change related to each of the four ACP domains (Sudore et al., 2013), but have since been eliminated in the new version of the ACPES (Sudore et al., 2017a). Figure 5 illustrates the interaction of the behavioral change processes and actions with the ACP domains (used with permission from Sudore et al., 2013).

Figure 5: *Interaction of ACP Domains, Behavioral Processes, and Actions*



In a diverse sample of 50 older adults from outpatient clinics, nursing homes, and community clinics and 20 younger healthy adults, Sudore (2013) found that the mean overall process measure score was 3.7 on a 5-point Likert scale ranging from not at all to extremely likely. The 20 younger healthy adults in the study had an overall process measure mean of 2.7, with the older adults having an overall process measure mean of 4.4. In the older adults, the mean total score for action measures (total possible score of 18) was 10.1, and the mean total score for action measures in the younger adults was 5.3. Comparisons between the demographic characteristics of the older and younger adults were also provided, although there were no data about possible correlations between these and the engagement scores. More of the older adults were extremely religious, and

just under one-half of them were married; these factors may have impacted the differences in scores. Prior advance care planning experience, including making decisions for others, was much more common in the older adults.

The ACPES has been tested for reliability and validity. One-week test-retest intraclass correlation (ICC) was used to estimate the survey's reliability and indicates the survey measures the outcome the same way, in a stable study participant, each time it is used (Tabachnick & Fidell, 2012). ICC values over 0.8 indicate almost perfect agreement; ICC values of 0.7 to 0.8 indicate strong agreement; and ICC values of 0.5 to 0.6 indicate moderate agreement. The ICC for the ACPES was 0.70 for process measures overall (Sudore et al., 2013). For each subscale of knowledge, contemplation, self-efficacy, and readiness, the one-week test-retest ICCs were 0.70, 0.56, 0.60, and 0.69, respectively (Sudore et al., 2013). Cronbach's alpha was also calculated to estimate internal consistency; this test should have a value above 0.7 (Tabachnick & Fidell, 2012). Cronbach's alpha was calculated as 0.94 for the process measures overall (Sudore et al., 2013). It was calculated as 0.84, 0.86, 0.83, and 0.92 for each subscale of knowledge, contemplation, self-efficacy, and readiness, respectively (Sudore et al., 2013). For the action measures, the overall ICC was 0.87 and was 0.81, 0.87, 0.83, and 0.57 for the subscales of decision makers, quality of life, flexibility, and asking questions, respectively (Sudore et al., 2013).

The ACPES was recently modified and tested for feasibility in a convenience sample of 196 patients from primary care practices, hospitals, cancer care centers, and dialysis centers (Howard et al., 2016). The modifications included 33 additional unvalidated questions; 18 questions were added to the quality of life domain and 12

questions were added to the decision makers domain. The three remaining additional questions related to readiness to decide on a healthcare decision maker. The time to complete the modified survey averaged from 34 minutes to one hour, leading the researchers to conclude that it may not be feasible to administer the lengthy survey in a hospital setting (Howard et al., 2016). However, questions about acceptability of the survey yielded means from good to very good from the study participants and indicated that the participants did not find the survey burdensome to complete (Howard et al., 2016).

The ACPES has been further modified to become shorter and more feasible, and then tested to reflect validity of shorter versions (Sudore et al., 2017a). Sudore (2017a) tested the ACPES as 82, 55, 34, 15, nine, and four items with a sample of 664 patients of varying demographic characteristics. The 55-, 34-, and 15-item modifications were found to have internal consistency and construct validity similar to the 82-item survey. The smallest surveys, of nine and four items, were recommended for use in quality improvement settings or in clinical studies with limited resources.

Summary

ACP has been shown to improve quality of life and satisfaction with care, both at end of life and while people are coping with terminal illnesses. ACP has evolved from the completion of legal documents such as living wills and appointment of SDMs to an ongoing process that involves multiple behaviors. A person's involvement in ACP may be impacted by a variety of demographic factors, including age, marital status, education, and religiosity. Health factors, such as presence and severity of illnesses, may also impact a person's involvement. Engagement in ACP can be measured through the use of

Sudore's (2013) ACPES, which assesses factors such as discussion of values and preferences for care with family and healthcare providers, appointment of SDMs, and creation of living wills. Increasing knowledge of how the demographic and health factors impact engagement in ACP will help in the development of interventions that increase involvement in ACP, which then in turn will improve quality of life and satisfaction with care.

CHAPTER 3

METHODS

This chapter will provide a description of the methods used to assess the relationship between heart failure and advance care planning in the study.

Design

A descriptive correlational study design was used to measure the frequency of advance care planning among a sample of patients with heart failure and to examine the relationship between their engagement in advance care planning and their ACCF/AHA heart failure stage, comorbid conditions, perception of health status, and recent hospitalizations. Data was collected from participants using a self-report survey distributed by mail.

Research Aims

The specific aims and research questions of the study were:

Specific Aim 1: To describe advance care planning engagement in patients with heart failure.

Research questions for Specific Aim 1 include:

- 1A. What are the characteristics of patients who are participating in this study of advance care planning?
- 1B. What percentage of patients in this study report having appointed a surrogate decision-maker for health care decisions?
- 1C. What percentage of patients in this study report discussions of values and goals of care with surrogate decision-makers?

1D. What percentage of patients in this study report discussions of values and goals of care with healthcare providers?

1E. What percentage of patients in this study report having completed advance directives?

Specific Aim 2: To explore the association between patient engagement in advance care planning and ACCF/AHA heart failure stage; NYHA heart failure class; comorbidity index; patient perception of health status; recent hospitalizations; and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, and religiosity.

Research questions for Specific Aim 2 include:

2A. What is the strength of the association between engagement in advance care planning and ACCF/AHA heart failure stage?

2B. What is the strength of the association between engagement in advance care planning and NYHA heart failure class?

2C. What is the strength of the association between engagement in advance care planning and patient comorbidities?

2D. What is the strength of the association between engagement in advance care planning and patient perception of health status?

2E. What is the strength of the association between engagement in advance care planning and any recent hospitalizations?

2F. What is the strength of the association between engagement in advance care planning and making healthcare decisions for others?

2G. What is the strength of the association between engagement in advance care planning and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, religion, and health literacy?

Setting

Study participants were recruited from the offices of The Ohio Heart and Vascular Center (OHVC), a division of The Christ Hospital Physicians, in Cincinnati, Ohio. The Christ Hospital is a 529-bed, not-for-profit, acute care teaching hospital in an urban area of Cincinnati, Ohio. It is rated as “high performing” in heart failure by U.S. News and World Report, indicating that the patient outcomes are significantly better than the national average (U.S. News, 2016). The Christ Hospital Physicians is the physician organization of The Christ Hospital Health Network. OHVC patients are primarily residents of Cincinnati, Ohio, and its surrounding suburbs. Each of the four heart failure physicians in the group sees approximately 800 to 1100 patients annually with differing stages of heart failure.

Sampling

The study population included patients with varying stages of heart failure. The study sample was drawn from those patients seen at the Ohio Heart and Vascular Center (OHVC) by cardiologists specializing in heart failure. This office uses the electronic medical software Epic, which contains demographic and diagnostic information including physical assessment data, diagnostic test reports, physician notes, and patient plans of care. The office staff ran a query on the electronic medical record database to obtain names of all patients seen for heart failure in the previous 13 months. Patients are seen,

at minimum, on an annual basis, so this time frame was chosen to capture all active patients.

After OHVC staff identified the potential participant pool, a list of their names was provided to the investigator. The investigator received access to Epic through OHVC after The Christ Hospital's IRB approved the current study. For recruitment purposes only, the investigator reviewed the electronic medical records of the identified OHVC heart failure patients to determine whether the patients met the inclusion criteria. The criteria for inclusion in the present study were:

1. diagnosis of heart failure;
2. under the care of The Ohio Heart and Vascular Physicians within the previous 13 months; and
3. age 18 or older.

Exclusion criteria included:

1. diagnosis of congenital heart disease;
2. diagnosis of dementia; or
3. required translator as noted in Epic.

Patients with congenital heart disease such as hypoplastic left heart syndrome, congenital valvular disorders, or septal defects were excluded because the trajectory of this type of heart disease is markedly different from those who are diagnosed with heart failure in adulthood. Those with a documented diagnosis of dementia were excluded to help ensure that study participants had the capacity both to consent to participate and to engage in advance care planning.

The researcher identified the ACCF/AHA heart failure stage (A, B, C, or D – see description in Chapter 2) and NYHA heart failure class (1, 2, 3, or 4 – see description in Chapter 2) of each potential participant by querying the electronic medical record, as this information is routinely documented by the OHVC providers. The researcher then employed disproportionate stratified sampling. Stratified sampling refers to the division of the population into separate groups, called strata. With disproportionate stratified sampling, the sample size of each stratum does not have to be proportionate to the population size of the stratum. The intent was to achieve approximately equal numbers of participants of each ACCF/AHA stage of heart failure (stages A through D). However, because there were fewer patients in stage D, there were not enough potential participants in Stage D to construct groups of the same size. In order to increase the total number of surveys mailed, additional participants from Stage C received surveys, because this was the next closest stage in severity. The initial mailing included 125 participants in Stage A, 125 in Stage B, 192 in Stage C, and 58 in Stage D. A second mailing was sent to 363 nonresponders from the initial sample along with 140 new participants. A third mailing was added and the survey was sent to 67 new participants.

Sample Size

Sample size is an important consideration in study planning and necessary for the reduction of Type II errors. Necessary sample size was calculated based on a power analysis with a desired power of 0.8. Power analysis for a regression analysis with 39 predictors was conducted online using the program G*Power to determine a sufficient sample size using an alpha of 0.05, a power of 0.80, and a medium effect size ($f^2 = 0.15$) (Faul, Erdfelder, Lang, & Buchner, 2007). Based on the aforementioned assumptions,

the desired sample size was 211. With 39 predictors, however, the ideal sample size was 390, and thus the overall goal was to receive completed surveys from approximately 100 participants from each stage of heart failure.

Human Subjects Protection

The study protocol was approved by the Institutional Review Boards at Indiana University–Purdue University (IUPUI) in Indianapolis, Indiana and The Christ Hospital in Cincinnati, Ohio. The survey was deemed expedited under category 7 because it “involve[d] no more than minimal risk” to the study participants (45 C.F.R. § 46.110(b)(1)).

The IU IRB also served as the HIPAA review board. An initial waiver of HIPAA authorization for recruitment was requested from the IRB. The waiver allowed the investigator to review electronic medical records to identify potential study participants. Once identified, each potential participant was assigned a randomly generated number. A key containing the numbers and names of potential participants was stored in a password-protected, secure database accessible only by the principal investigators. Names were retained for the sole purpose of personalizing the introductory letter sent to potential participants.

Potential participants received an introductory letter and information sheet that contained the elements of informed consent but did not require a signature. The information sheet included an explanation of the research, a contact number for the investigator, and a contact number for the Indiana University IRB in case of questions about their rights as a research participant. It also included a statement about the risk of the research, which was a potential loss of confidentiality. Consent was implied when

participants completed and returned the survey to the investigator. All participants who returned the survey within two weeks and provided their contact information were entered into a drawing for three \$50 gift cards to a local grocer of their choice; those who returned the materials after the reminder were entered into a drawing for three \$25 gift cards to a local grocer of their choice. The investigator examined medical records of those participants who returned the survey in order to ascertain comorbid conditions, one of the predictor variables in the model.

Measures

Engagement in Advance Care Planning

The primary dependent variable in this study was engagement in advance care planning. This variable was measured by the Advance Care Planning Engagement Survey (ACPES), developed and modified by Sudore and colleagues (2017). The ACPES is based on Prochaska's Trans-Theoretical Model (TTM), which was developed to understand the stages of change and the processes related to change (Prochaska, DiClemente, & Norcross, 1992). The TTM includes multiple actions and adaptations that occur over time. As described in Chapter 2, the stages of changes assess a person's readiness to act on a new behavior; a person may cycle through the stages in a "spiral" or revert back to an earlier stage at any time (Prochaska, DiClemente & Norcross, 1992). The five stages of change are: (1) precontemplation; (2) contemplation; (3) preparation; (4) action; and (5) maintenance (Prochaska & Velicer, 1997). The ACPES also incorporates Social Cognitive Theory and Behavior Change Theory, which indicate that any change in behavior requires an individual to change several factors related to any particular behavior, including: (1) *knowledge* of the importance of the behavior; (2)

contemplation about the behavior; (3) *self-efficacy* to perform the behavior; and (4) *readiness* to perform the behavior (Sudore et al., 2013).

The ACPES includes four domains: *decision makers*, *quality of life*, *flexibility*, and *asking questions*. The ACPES measures cognitive processes related to each domain using 5-point Likert-style questions. The questions are based on how much an individual has thought about ACP-related topics, including personal values and goals of healthcare and the appointment of a surrogate decision maker. The 5-point scale asks respondent to rate their answers from one, meaning “not at all,” to five, meaning “extremely.”

The questions in the ACPES are categorized according to the sub-scales of *knowledge*, *contemplation*, *self-efficacy*, and *readiness* described above. The *knowledge* subscale asks how well informed the respondent is about the domains of decision makers, flexibility, and asking questions (quality of life is not part of this subscale). The *contemplation* subscale asks how much the respondent has thought about items in each subscale. The *self-efficacy* subscale asks how confident the respondent is that they could do these actions on that day. Finally, the *readiness* subscale asks how ready the respondent is to do these actions on that day.

The *decision makers* domain includes ten questions about identification of a surrogate decision maker and informing them and the providers of the responsibility. The *quality of life* domain is divided into *health situations* (seven questions) and *medical care at the end of life* (nine questions) and includes questions about the identification of the person’s values and goals and communicating them to the surrogate and provider. The *flexibility* domain includes six process measure questions about communicating the amount of leeway the surrogate will have in making decisions. Finally, the *asking*

questions domain includes two questions asking the respondent about preparedness to ask providers questions in order to make informed care decisions.

The overall Cronbach's alpha for the 34-question ACPES is 0.96 (Sudore et al., 2017), with intra-class correlations ranging from 0.54 – 0.82 (Sudore et al., 2013). One-week test-retest intraclass correlation (ICC) was used to estimate the survey's reliability; this test indicates whether the survey measures the outcome the same way, in a stable study participant, each time it is used (Tabachnick & Fidell, 2012). ICC values over 0.8 indicate almost perfect agreement; ICC values of 0.7 to 0.8 indicate strong agreement; and ICC values of 0.5 to 0.6 indicate moderate agreement. The ICC for the ACPES was 0.70 for process measures overall (Sudore et al., 2013). For each subscale of *knowledge*, *contemplation*, *self-efficacy*, and *readiness*, the one-week test-retest ICCs were 0.70, 0.56, 0.60, and 0.69, respectively (Sudore et al., 2013). Cronbach's alpha was also calculated to estimate internal consistency; this test should have a value above 0.7 (Tabachnick & Fidell, 2012). Cronbach's alpha was calculated as 0.96 for the process measures overall (Sudore et al., 2013). It was calculated as 0.84, 0.86, 0.83, and 0.92 for each subscale of *knowledge*, *contemplation*, *self-efficacy*, and *readiness*, respectively (Sudore et al., 2013).

ACCF/AHA Heart Failure Stage and NYHA Heart Failure Class

ACCF/AHA heart failure stage and NYHA heart failure class are routinely documented by OHVC providers during the usual course of patient care. ACCF/AHA Stage is based on objective information and gives providers data about physical changes in the heart, while NYHA Class is based upon a patient's self-report of symptoms. Both of these variables are used by providers to determine a patient's treatment plan. The

information on stage and class was retrieved from the medical record by the investigator during the initial screening of potential participants.

Comorbidity

The independent variable comorbidity was measured using the Charlson Comorbidity Index (CCI) (Charlson, Pompei, Ales, & MacKenzie, 1987). See Appendix B. The CCI uses data collected from the medical record by the researcher, including both the patient's age and the presence of certain other disease processes such as heart failure, cancer, and liver disease. Each of the comorbid conditions measured in the CCI has a correlative ICD-10 code that can be queried within an electronic medical record.

The CCI contains 17 categories of comorbidities that are assigned weights of one, two, three, or six points, based on the adjusted risk of mortality from that factor (Charlson et al., 1987). Patients receive one point for each of the following disorders: myocardial infarction; heart failure; peripheral vascular disease; cerebrovascular accident with mild or no residual; dementia; chronic pulmonary disease; connective tissue disease; peptic ulcer disease; mild liver disease, without portal hypertension; diabetes without end-organ damage, unless diet-controlled; and age over 40 years, with one additional point given per decade. Patients receive two points for each of the following disorders: diabetes with end-organ damage; hemiplegia or paraplegia; moderate or severe renal disease; and malignancies diagnosed within the previous five years, except skin. Patients receive three points for moderate or severe liver disease. Finally, they receive six points for a metastatic tumor or a diagnosis of AIDS. The overall CCI score reflects the increased likelihood of one-year mortality, with higher scores indicating higher risk. The CCI has

been tested multiple times and demonstrates good test-retest and interrater reliability (De Groot, Beckerman, Lankhorst, & Bouter, 2003; Quan et al., 2011).

Patient Perception of Health Status

Patient perception of health status was assessed based on participant responses to three questions. The first question states “In general, would you say your health is:” and provides participants with five response options (excellent, very good, good, fair, or poor). The second question states “Compared to a year ago, how would you rate your health in general now?” The response options range from “Much better” to “Much Worse” than one year ago. The third question asks “How are you feeling today?” and gives five options ranging from excellent to poor.

The first two questions were taken from the SF-36, an instrument widely validated to assess quality of life (Failde & Ramose, 2000; Jenkinson, Wright, & Coulter, 1994; Ruta et al., 1994). Recent tests of reliability and validity show an overall Cronbach’s Alpha coefficient of 0.791 (Zhang et al., 2012). The third question was taken from pilot work that involved cognitive interviews with five patients to determine its feasibility in the heart failure population. Three of the five patients indicated that their responses to the ACPES would depend on how they were feeling at the time they took the survey. Each question was analyzed separately as described in chapter three.

Recent Hospitalizations

Participants were asked if they have been hospitalized within the last six months for more than an overnight stay. This question had dichotomous yes/no responses for them to select.

Sociodemographic Variables

Patients received a background questionnaire (Appendix B) on which they were asked their age, gender, ethnicity, marital status, religious preference, and education level.

Income was assessed by asking two questions on the background questionnaire. Participants were first asked, “When you consider your total household income, would you say that you are comfortable, have just enough to make ends meet, or do NOT have enough to make ends meet?” and provided with those three options. Second, they were asked their total annual household income before taxes and be provided with ranges from “under \$25,000” to “over \$100,000.” Options of “unknown” and “decline to answer” were be provided.

Health Literacy

Health literacy was assessed using three questions on the background questionnaire. The first question asked, “How confident are you filling out medical forms?” and provided participants with 5 response options (excellent, very good, good, fair, or poor). The second question asked, “How often do you have problems learning about your medical condition because of difficulty understanding written information?” The final question was “How often do you have someone help you read hospital materials?” These questions had five response options ranging from “almost all of the time” to “never.” These questions have been previously used in surveys to identify patients with inadequate health literacy, and have been shown to be effective replacements for the Short Test of Functional Health Literacy in Adults (Chew, Bradley, & Boyko, 2004; Wallace et al., 2006).

Study Procedures

Upon approval by the dissertation committee, the protocol was submitted to the Indiana University Institutional Review Board (IU IRB) for approval. Once approved, the documentation was sent to the IRB of The Christ Hospital, but the IU IRB was the IRB of record. Once IRB approval from The Christ Hospital was received, staff at OHVC ran an initial query to obtain names and medical record numbers of all current patients with a diagnosis of heart failure. The study investigator then reviewed the electronic health record of all individuals seen by OHVC heart failure physicians for screening purposes only. The stratified sampling technique was used to ensure mailings went to potential participants in each heart failure stage. Each participant was assigned a random identification number; a key to these numbers was retained to track participants that returned their questionnaires after the first mailing.

A survey packet was prepared for each potential participant that had the patient's randomly generated identification number. Names were retained for the sole purpose of ascertaining those who needed reminder letters and delivering survey incentives. As part of the survey packet, potential participants received an introductory letter from their cardiologist at OHVC that introduced the investigator and asked them to complete the study. The packet also contained a letter of information about the study (Appendix A), the background questionnaire (Appendix B), and the ACPES (Appendix C). The background questionnaire and ACPES were coded with the participants' random identification numbers. Participants were also informed about the study incentives: those who completed the survey within two weeks were entered into a drawing for three \$50 gift cards to a local grocer of their choice; those who returned the materials after the

reminder were entered into a drawing for three \$25 gift cards to a local grocer of their choice. The packet also contained a card for the participant to complete with their contact information for entry into the gift card drawings. The packets were sent via U.S. mail, along with a postage-paid return envelope.

Returned surveys were checked against the key to determine those who had not responded within two weeks. Participants who did not return the study materials within two weeks received a reminder letter and a second copy of the materials. Packets returned to sender were checked for address accuracy, but new addresses were not available for any of them. They were thus removed from the participant list.

Data Analysis

Analysis for each study aim was performed using SPSS. The level of statistical significance for all analyses was set at $p \leq .05$ to decrease the risk of Type 1 error. Type 1 errors occur when a correct null hypothesis is rejected (Tabachnick & Fidell, 2013). Because there were multiple hypotheses to be tested in this study, the likelihood of a Type 1 error increased. This would result in a false finding of statistical significance. Adjusting the p value, such as through the Bonferroni method, decreases the chance of a Type 1 error, but necessitates an increase in sample size or increases the likelihood of a Type 2 error (Feise, 2002). In this study, the rate of return was sufficient to produce a sample size large enough to preserve power with the Bonferroni adjustment applied.

The independent variables in this study were ACCF/AHA stage, CCI, recent hospitalizations, age, gender, ethnicity, marital status, income, education level, religion, and health literacy level. Table 3 illustrates how the data was reported and entered for statistical analysis.

Table 3: *Predictor Variables*

Predictor Variable	Type of Variable	Response Coding
ACCF/AHA Stage	Categorical	A, B, C, or D
NYHA Class	Categorical	1, 2, 3, or 4
CCI	Continuous	0–28
Recent hospitalizations	Dichotomous, categorical	0 = no 1 = yes
Age	Categorical	0 = under 40 1 = 41 to 50 2 = 51 to 60 3 = 61 to 70 4 = over 70
Gender	Categorical	0 = male 1 = female
Ethnicity	Categorical	0 = African-American or Black 1 = Caucasian or White 2 = Asian 3 = American Indian or Native Alaskan 4 = Native Hawaiian or Pacific Islander 5 = Hispanic or Latino
Marital Status	Categorical	0 = single 1 = married 2 = widowed or widower 3 = divorced 4 = living with partner
Income range	Categorical	0 = under \$25,000 1 = \$25,000 – \$49,999 2 = \$50,000 – \$74,999 3 = \$75,000 – \$9,999 4 = \$100,000 or more
Making ends meet	Categorical	0 = comfortable 1 = just enough to make ends meet 2 = not enough
Education level	Categorical	0 = grammar school 1 = high school or equivalent 2 = vocational or technical school 3 = some college 4 = Bachelor degree 5 = Master’s degree 6 = doctoral degree 7 = professional degree
Religion	Categorical	0 = Protestant

Predictor Variable	Type of Variable	Response Coding
		1 = Catholic 2 = other Christian 3 = Mormon 4 = Jewish 5 = Muslim 6 = other non-Christian religion 7 = no religion

Key: ACCF = American College of Cardiology Foundation; AHA = American Heart Association; CCI = Charlson Comorbidity Index; NYHA = New York Heart Association.

The dependent variable in this study was engagement in ACP as measured by the ACPEs. Numerical values were assigned to the 5-point Likert. A total process measure score was calculated, with a range from 31 to 155 points. Total scores for each subscale of knowledge, contemplation, self-efficacy, and readiness were also calculated, with ranges of 6 to 30 points, 9 to 45 points, 6 to 30 points, and 10 to 50 points, respectively.

Initial analysis consisted of the calculation of descriptive statistics for all variables. For independent variables, this assisted in evaluating the quality of the data and to identify any patterns of missing and out-of-range values. CCI, a continuous variable, was reported as mean (M) and standard deviation (SD). Frequency and percentages of the categorical variables (ACCF/AHA stage, recent hospitalizations, age, gender, ethnicity, marital status, income, education level, religiosity, and health literacy level) were calculated. The process measures were described using mean and standard deviation, overall and for each subscale.

Specific Aim 1 examined characteristics of the patients participating in the study.

Aim 1A: What are the characteristics of patients who are participating in this study of advance care planning? Descriptive statistics were run on each independent variable (see Table 5).

Aim 1B: What percentage of patients in this study report having appointed a surrogate decision-maker for health care decisions? The background questionnaire included the following questions: “Have you already formally asked someone to be your medical decision maker” and “Have you signed official papers naming a person or group to make medical decisions for you?” Frequencies and percentages of yes and no responses were tabulated and reported.

Aim 1C: What percentage of patients in this study report discussions of values and goals of care with surrogate decision-makers? The background questionnaire included the following questions: “Have you talked with your medical decision maker about whether certain health situations would make your life not worth living,” and “Have you talked to your medical decision maker about how much flexibility you want to give her/him?” Frequencies and percentages of yes and no responses were tabulated and reported.

Aim 1D. What percentage of patients in this study report discussions of values and goals of care with healthcare providers? The background questionnaire included the following questions: “Have you talked to your doctor about who you want your medical decision maker to be,” and “Have you talked with your doctor about whether certain health situations would make your life not worth living?” Frequencies and percentages of yes and no responses were tabulated and reported.

Aim 1E: What percentage of patients in this study report having completed advance directives? The background questionnaire included the following questions: “Have you signed official papers naming a person or group to make medical decisions for you;” “Have you signed official papers about your wishes for medical care if you were

seriously ill or dying;” and “Have you signed official papers to put your wishes about how much flexibility to give your decision maker in writing?” Frequencies and percentages of yes and no responses were tabulated and reported.

For each subsection of Aim 1, frequencies and percentages of yes and no responses were further broken down by the four ACCF/AHA stages A, B, C, and D to assess frequency and percentage of each behavior in each stage of heart failure.

Specific Aim 2 examined the strength of association between engagement in advance care planning and several variables.

Aim 2A. What is the strength of the association between engagement in advance care planning and ACCF/AHA heart failure stage?

Aim 2B. What is the strength of the association between engagement in advance care planning and NYHA heart failure class?

Aim 2C. What is the strength of the association between engagement in advance care planning and patient comorbidities?

Aim 2D. What is the strength of the association between engagement in advance care planning and patient perception of health status?

Aim 2E. What is the strength of the association between engagement in advance care planning and any recent hospitalizations?

Aim 2F. What is the strength of the association between engagement in advance care planning and making healthcare decisions for others?

Aim 2G. What is the strength of the association between engagement in advance care planning and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, religion, and health literacy?

For Aim 2, a regression analysis was conducted to assess if the independent variables heart failure stage, heart failure class, comorbidity index, patient perception of health status, and recent hospitalizations predict the dependent variable engagement in advance care planning. A review of the research does not elicit any information about the order of the predictor variables or about the importance of them in relation to the dependent variable advance care planning. The assumptions of multiple regression include linearity, independence of residuals, homoscedasticity, and absence of collinearity. When the assumptions are not met, the results may result in Type I or Type II errors, or over- or under-estimation of effect size.

Linearity assumes a straight-line relationship between the predictor variables and the dependent variable, and was tested by a scatter plot. Independence of errors means that errors are independent of one another, which indicates that participants are responding independently, and was assessed by plotting the studentized deleted residuals against the predicted values. A pattern that is not random suggests a lack of independence of errors. Homoscedasticity refers to equal variance of errors for all values of the predictor variables and was assessed by scatter plots of the residuals. Finally, the absence of collinearity assumes that predictor variables are independent from each other and thus allows the researcher to interpret the regression coefficients as the effects of the predictor variables on the dependent variable. Collinearity was assessed using Variance Inflation Factors (VIF) in SPSS. VIF values of 1 indicate a lack of collinearity between factors, while any value over 1 indicates some correlation. VIF values over 10 will suggest high correlation between the factors, and potentially problematic collinearity. If variables violate the assumption of collinearity, there are methods of adjustment,

including removing highly correlated predictors from the model. Such predictors would be indicated by high VIF values and could imply redundant information. Other options would be to use principal components analysis to construct factor scores, which are orthogonal, from the collinear variables. In addition, diagnostic plots of residuals and measures of influence (for example, Cook's distance) will be produced to identify potential outlying and influential observations. Such outliers may merely be extreme values of a variable, and thus should be retained. However, they may be the result of an error in calculation or even data collection.

The F-test was used to test the linear association between the set of independent variables collectively and the dependent variable. R-squared (the multiple correlation coefficient of determination) was reported and used to determine proportion of variance in engagement accounted for by the set of independent variables (ACCF/AHA stage, comorbidity index, patient perception of health status, and recent hospitalizations). Adjusted R-squared was also calculated, as this value accounts for the number of independent variables and sample size, and thus is more reflective of generalizability to the population. Beta coefficients were used to determine the magnitude of linear association for each independent variable.

Bivariate measures of association appropriate for the level of measurement were reported for the continuous predictor with each independent variable. Chi-square tests were calculated and reported to accomplish the same for all pairs of independent and dependent categorical variables. Multiple linear regression was used to determine the degree to which independent variables predict engagement in advance care planning when controlling for all other independent variables.

CHAPTER 4

RESULTS

The purpose of this study was to gain knowledge about engagement in advance care planning in participants diagnosed with heart failure and to evaluate the impact of certain variables (ACCF/AHA heart failure stage; comorbidity index; participant perception of health status; recent hospitalizations; and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, and religiosity) on engagement in advance care planning. This chapter reports the results from the study.

Specific Aims and Hypothesis Testing

Aim 1

Question 1A: What are the characteristics of the patients who are participating in this study of advance care planning?

The population examined consisted of adult participants who were seen by the physicians at Ohio Heart and Vascular Center in Cincinnati, Ohio between July 2016 and May 2018. A total of 1067 surveys were mailed to 716 potential study participants, of which 233 were returned, resulting in a response rate of 32.6%. The mailings were intended to evenly stratify participants by stage; however, there were not enough potential participants in Stage D to construct groups of the same size. In order to increase the total number of surveys mailed, additional participants from Stage C received surveys because this was the next closest stage in severity. The initial mailing included 125 participants in Stage A, 125 in Stage B, 192 in Stage C, and 58 in Stage D. A second mailing was sent to 363 nonresponders from the initial sample along with 140 new participants. A third mailing was added and the survey was sent to 67 new participants.

A chi-square goodness of fit test was used to compare responders and nonresponders as to heart failure stages and classes. Statistically significant differences were seen when comparing responders and non-responders as to heart failure stage, $X^2(3, N = 706) = 97.128, p < 0.01$, and as to heart failure class, $X^2(7, N = 706) = 140.6, p < 0.01$. There was no statistically significant difference between responders and non-responders as to gender, $X^2(1, N = 706) = 0.5495, p = 0.46$. Table 4 shows the chi-square and significance values for the responders and nonresponders with respect to gender, Stage, and Class. Because only six of the study participants were in Stage D heart failure, their data were combined with those in Stage C for all of the analyses.

Table 4: Comparison of Survey Responders' and Nonresponders' Characteristics

	Total n = 706 n (%)	Responders n = 233 n (%)	Nonresponders n = 483 n (%)	Chi-square test
Gender				
Male	383 (54.2)	120 (31.3)	263 (68.7)	$X^2 = 0.55$ $p = 0.46$
Female	323 (45.8)	113 (35.2)	220 (64.8)	
ACCF/AHA Heart Failure Stage				
A	132 (18.7)	11 (8.3)	121 (91.7)	$X^2 = 97.13$ $p < 0.01$
B	207 (29.3)	59 (28.5)	148 (71.5)	
C	308 (43.6)	157 (51.1)	151 (48.9)	
D	59 (8.4)	6 (10)	53 (90)	
NYHA Heart Failure Class				
N/A ^a	132 (18.7)	11 (8.3)	121 (91.7)	$X^2 = 140.6$ $p < 0.01$
1	204 (28.9)	59 (28.9)	145 (71.1)	
1-2	12 (1.7)	9 (75)	3 (25)	
2	151 (21.4)	86 (57.2)	65 (42.8)	
2-3	73 (10.3)	15 (20.5)	58 (79.5)	
3	74 (10.5)	47 (63.5)	27 (36.5)	
3-4	3 (0.4)	1 (33.3)	2 (66.7)	
4	57 (8.1)	4 (7)	53 (93)	

Key: ACCF/AHA = American College of Cardiology Foundation/American Heart Association. NYHA = New York Heart Association.

Notes: ^a Stage A participants have no symptoms and thus are not assigned to a NYHA Heart Failure Class.

Slightly more than half (51.5%, n=120) of the participants were male, with the majority of the participants over age 70 (57.5%, n=134) and married (56.7%, n=132). The majority of the participants (56.2%, n=131) identified as Caucasian or white, with 39% (n=91) identifying as African American or black. The majority (73.4%, n=171) of participants had at least some college education and identified as Christian (86.7%, n=202). Table 5 summarizes participant demographic characteristics.

Table 5: *Demographic Characteristics of Participants*

Characteristic (n=233)	n (%)
Gender	
Male	120 (51.5)
Female	113 (48.5)
Age	
41 – 50 years	12 (5.2)
51 – 60 years	27 (11.6)
61 – 70 years	55 (23.6)
Over 70 years	134 (57.5)
Race	
African American or black	92 (39)
Caucasian or white	132 (56.2)
Asian	9 (3.8)
Not Hispanic/Latino	209 (89.7)
Marital Status	
Married	132 (56.7)
Single	37 (15.9)
Widowed/widower	32 (13.7)
Divorced	31 (13.3)
Income	
Comfortable	119 (51.1)
Just enough to make ends meet	75 (32.2)
Not enough to make ends meet	31 (13.3)
Under \$24,999	35 (15)
\$25,000 to \$49,999	52 (22.3)
\$50,000 to \$74,999	29 (12.4)
\$75,000 to \$100,000	23 (9.9)
Over \$100,000	43 (18.5)
Education	
Grammar school	3 (1.3)
Vocational/technical school (2 year)	6 (2.6)
High school or equivalent	44 (18.9)
Some college	65 (27.9)
Bachelor degree	49 (21)
Master's degree	29 (12.4)
Doctoral or professional degree	28 (11)
Residence	
Urban	65 (27.9)
Suburban	148 (63.5)
Rural	20 (8.6)
Religion	
Protestant	80 (34.3)
Catholic	90 (38.6)

Characteristic (n=233)	n (%)
Other Christian	32 (13.7)
Jewish	2 (0.9)
No religion	15 (6.4)

The participants were also asked about their current health status and rated it from *excellent* to *poor*. A majority rated their health as *fair* or better (84%, n=193). The participants also reported their health status compared to one year ago, and the majority (70.9%, n=163) reported that it was *about the same*. They were also asked about how they were feeling the day they took the survey, from *excellent* to *poor*, and a majority (41.3%, n=95) stated that they felt *fair*, with another 38.7% (n=89) stating they felt *good*. About half (52.8%) had been hospitalized for more than an overnight stay within the past six months. Table 6 presents the details of these characteristics of the study participants.

Table 6: *Self-Reported Health Status of Participants*

Characteristic (n=230)	n (%)
Current Health Status ^a	
Excellent	2 (0.9)
Very good	16 (7)
Good	75 (32.6)
Fair	100 (43.5)
Poor	37 (16.1)
Health Compared to 1 Year Prior ^a	
Much better	2 (0.9)
Somewhat better	5 (1.5)
About the same	163 (70.9)
Somewhat worse	54 (23.5)
Much worse	6 (2.6)
How Feeling Today ^b	
Excellent	2 (0.9)
Very good	17 (7.4)
Good	89 (38.7)
Fair	95 (41.3)
Poor	26 (11.3)
Hospitalization During Last 6 Months	
	123 (52.8)

Notes. ^aThe first two questions were taken from the SF-36 measure (Ware & Sherbourne, 1992). ^bThe third question was added based on cognitive interviews based on pilot work done by the researcher.

Most of the study participants reported adequate health literacy skills and confidence in learning about their health conditions. A majority (42.2%, n=97) reported their confidence in completing medical forms as *excellent*, with another 28.3% (n=65) reporting their confidence as *very good*. When asked if they had difficulty understanding medical information, 28.2% (n=64) reported they never had difficulty, with another 43.6% (n=99) stating they rarely had difficulty. The majority (47.6%, n=109) of participants also stated that they never had to have someone help them read. These data are summarized in Table 7.

Table 7: *Health Literacy of Participants*

Characteristic	n (%)
Confidence in Completing Forms (n=230)	
Excellent	97 (42.2)
Very good	65 (28.3)
Good	47 (20.4)
Fair	13 (5.7)
Poor	8 (3.5)
Difficulty Understanding (n=227)	
Never	64 (28.2)
Rarely	99 (43.6)
Occasionally	47 (20.7)
Frequently	14 (6.2)
Almost all of the time	3 (1.3)
Have Someone Help You Read (n=229)	
Never	109 (47.6)
Rarely	65 (28.4)
Occasionally	29 (12.7)
Frequently	19 (8.3)
Almost all of the time	7 (3.1)

Note: Scores on the three questions were averaged for statistical analysis.

Question 1B: What percentage of participants with heart failure in this study report having appointed a surrogate decision-maker for healthcare decisions?

The majority of participants in this study (59.7%, n=139) reported that they have formally asked someone to be a surrogate decision-maker (SDM) for healthcare

decisions; 97.1% of those participants (n=135) have already signed official documents. Only 10.7% (n=25) reported that they had never thought about it. A chi-square test of independence was performed to examine the relation between heart failure stage and asking someone to be an SDM. The relationship between these variables was not statistically significant, $\chi^2(8, N = 232) = 9.206, p = 0.33$. Table 8 summarizes the data related to the appointment of a surrogate decision-maker.

Table 8: *Appointment of Surrogate Decision-Maker by Heart Failure Stage*

	Total (n=233)	A n=11 n (%)	B n=59 n (%)	C & D n=163 n (%)
Status of Appointment				
Already formally asked	139 (59.7)	5 (45.5)	36 (61)	99 (71.2)
Planning to formally ask within next 30 days	4 (1.7)	0 (0)	0 (0)	4 (2.5)
Thinking about formally asking within next 6 months	16 (6.9)	1 (9)	3 (5.1)	12 (7.4)
Thought about formally asking, but not ready to do it	49 (20.6)	5 (45.5)	15 (25.4)	29 (17.8)
Never thought about formally asking	25 (10.7)	0 (0)	5 (8.5)	20 (12.3)
Official Documents				
Already signed official papers	135 (57.9)	4 (36.4)	35 (59.3)	96 (58.9)
Planning to sign papers within 30 days	5 (2.1)	1 (9.1)	0 (0)	4 (2.5)
Thinking about signing official papers within next 6 months	35 (15)	2 (18.2)	10 (16.9)	23 (14.1)
Thought about signing official papers, but not ready to do it	30 (12.4)	4 (36.4)	6 (10.2)	20 (12.2)
Never thought about signing official papers	28 (12)	0 (0)	8 (13.6)	20 (12.2)

Question 1C: What percentage of participants in this study report discussions of values and goals of care with surrogate decision-makers?

The majority of participants in this study (56%, n=130) reported that they have discussed their goals of care with their surrogate decision-makers (SDM). Nineteen

percent (n=44) reported that they had never thought about it. When broken down by HF stage, 36.4% (n=4) of participants with Stage A have discussed their goals of care with their surrogate decision-makers, with 57.1% (n=32) in Stage B, 60% (n=90) in Stage C, and 66.7% (n=4) in Stage D having done so. A chi-square test of independence was performed to examine the relation between heart failure stage and discussions of goals of care with their SDM. The relationship between these variables was significant, $X^2(8, N = 222) = 28.304, p < .01$, indicating that there is a statistically significant relationship between heart failure stage and whether or not someone has discussed their goals of care with a surrogate decision-maker. Table 9 summarizes the data related to the discussion of goals of care with a surrogate decision-maker.

Table 9: *Discussion of Values and Goals of Care with Surrogate Decision-Makers by Heart Failure Stage*

	Total (n=223)	A n=11 n (%)	B n=56 n (%)	C & D n=156 n (%)
Status of Discussion				
Already done	130 (58.3)	4 (36.4)	32 (57.1)	94 (60.3)
Planning to do it within next 30 days	4 (1.8)	1 (9.1)	1 (1.8)	2 (1.3)
Thinking about doing it within next 6 months	24 (10.8)	2 (18.2)	5 (8.9)	17 (10.9)
Thought about doing it, but not ready	29 (13)	3 (27.3)	7 (12.5)	19 (12.2)
Never thought about doing it	44 (19.7)	1 (9.1)	15 (26.8)	28 (17.9)

Question 1D: What percentage of participants with heart failure in this study report discussions of values and goals of care with healthcare providers?

The majority of participants in this study (87.9%, n=173) stated that they have not discussed their goals of care with their healthcare providers, although 26.1% (n=58) were

planning to do it within the next six months. Thirty-one percent (n=69) reported that they had never thought about it. A chi-square test of independence was performed to examine the relation between heart failure stage and discussion of goals of care with providers, and the relationship between these variables was significant, $X^2(8, N = 212) = 20.659, p < .01$. This indicates that there is a statistically significant relationship between heart failure stage and whether or not someone has discussed their goals of care with their healthcare providers. None of the participants in Stage A reported having discussed their goals of care with their providers, compared to 10.7% (n=6) in Stage B and 27.6% (n=43) in Stages C & D. Table 10 summarizes the data related to the discussion of goals of care with a healthcare provider.

Table 10: *Discussion of Values and Goals of Care with Provider by Heart Failure Stage,*

	Total (n=222)	A n=10 n (%)	B n=56 n (%)	C & D n=156 n (%)
Status of Discussion				
Already done	49 (22.1)	0 (0)	6 (10.7)	43 (27.6)
Planning to do it within next 30 days	6 (2.7)	0 (0)	1 (1.8)	5 (3.2)
Thinking about doing it within next 6 months	52 (23.4)	5 (50)	18 (32.1)	29 (18.6)
Thought about doing it, but not ready	46 (20.7)	1 (10)	5 (8.9)	40 (25.6)
Never thought about doing it	69 (31.1)	4 (40)	26 (46.4)	38 (25.6)

Question 1E: What percentage of participants with heart failure in this study report having completed advance directives?

The majority of participants in this study (56.9%, n=121) reported having completed advance directives, and an additional 15.6% (n=34) are planning to complete them within the next six months. Thirty-six percent (n=4) of participants with Stage A

have discussed their goals of care with their surrogate decision-makers, with 48.5% (n=32) in Stage B, and 56.3% (n=85) in Stage C, and 83.3% (n=5) in Stage D reporting these discussions. A chi-square test of independence was performed to examine the relation between heart failure stage and discussion of goals of care with providers, and the relationship between these variables was not statistically significant, $X^2(8, N = 217) = 11.147, p = 0.19$, showing that there is not a statistically significant relationship between heart failure stage and whether or not someone has completed advance directives. This indicates that heart failure stage is not associated with the completion of advance directives; the different failure stages had similar odds for completing advanced directives. Table 11 summarizes the data related to the completion of advance directives.

Table 11: *Completion of Advance Directives by Heart Failure Stage,*

	Total (n=218)	A n=11 n (%)	B n=56 n (%)	C & D n=151 n (%)
Status of Completion				
Already done	121 (56.9)	4 (36.4)	32 (48.5)	85 (56.3)
Planning to do it within next 30 days	5 (2.3)	1 (9.1)	1 (1.8)	3 (2.0)
Thinking about doing it within next 6 months	29 (13.3)	2 (18.2)	4 (7.1)	23 (15.2)
Thought about doing it, but not ready	40 (18.3)	4 (36.4)	14 (25)	22 (14.6)
Never thought about doing it	23 (10.6)	0 (0)	5 (8.9)	18 (11.9)

Aim 2

An ANOVA (analysis of variance) was performed to examine the relationship between the dependent variable of engagement score as measured by the Advance Care Planning Engagement Survey (ACPES) and the independent variables of Stage, CCI (Charlson Comorbidity Index), participant perception of health status, and

hospitalizations. A statistically significant association was found between the combination of these independent variables and the engagement score, $F(4,181) = 6.591$, $p < .01$. Each variable was also examined independently. Small cell sizes did not allow statistical testing of interaction effects.

Question 2A: What is the strength of the association between engagement in advance care planning and ACCF/AHA heart failure stage?

An ANOVA was performed to examine the relationship between the engagement score and heart failure stage. The ANOVA showed that there was no statistically significant association between stage and the engagement score, $F(1,187) = 0.966$, $p = 0.33$, indicating that ACCF/AHA heart failure stage is a poor predictor of engagement in advance care planning.

Question 2B: What is the strength of the association between engagement in advance care planning and NYHA heart failure stage?

An ANOVA was performed to examine the relationship between the engagement score and heart failure class. The ANOVA showed that there was no statistically significant association between class and the engagement score, $F(1,187) = 0.031$, $p = 0.70$, indicating that people in different NYHA heart failure classes had similar engagement scores.

Question 2C: What is the strength of the association between engagement in advance care planning and participant comorbidities?

An ANOVA was performed to examine the relationship between the engagement score and participant comorbidities, as quantified by the Charlson Comorbidity Index (CCI). The ANOVA showed that there was a statistically significant association between

the dependent variable CCI and the engagement score, $F(1,187) = 9.767$, $p < .01$. CCI is thus a significant predictor of engagement in advance care planning.

Question 2D: What is the strength of the association between engagement in advance care planning and participant perception of health status?

An ANOVA was performed to examine the relationship between the engagement score and each question participants were asked that pertained to health status. For the first question, participants were asked to rate their general state of health as *excellent*, *very good*, *good*, *fair*, or *poor*. The majority of participants (46.8%, $n=87$) rated their health as *fair*. The ANOVA showed that there was no statistically significant association between how a person rated their health status and the engagement score, $F(4,181) = 0.506$, $p = 0.73$. There was, however, a significant association between how a person rated their health as compared to one year prior, $F(4,181) = 3.090$, $p < 0.05$. Post hoc analyses were performed using Tukey HSD. Statistically significant differences were found between those participants rating their current health status as *about the same* and those rating it as *somewhat worse*. Those rating it *about the same* had higher mean engagement scores (127.5) than those rating it as *somewhat worse* (107.2). Finally, when asked about how they were feeling that day, participants rated themselves as feeling *excellent*, *very good*, *good*, *fair*, or *poor*. A majority (42.5%, $n=79$) stated they were feeling *fair*, closely followed by 40.3% ($n=75$) stating they were feeling *good*. The ANOVA showed that there was no statistically significant association between how a person was feeling that day and the engagement score, $F(4,181) = 1.119$, $p = 0.35$. A person's perception of health status was therefore not found to be a significant predictor, in general, of engagement in ACP.

Question 2E: What is the strength of the association between engagement in advance care planning and any recent hospitalization?

An ANOVA was performed to examine the relationship between the engagement score and the presence of any recent participant hospitalizations. The ANOVA showed that there was not a statistically significant association between recent hospitalizations and the engagement score, $F(1,187) = 0.883$, $p = 0.35$. The presence of recent hospitalizations is thus a poor predictor of engagement in advance care planning.

Question 2F: What is the strength of the association between engagement in advance care planning and making healthcare decisions for others?

Many participants (33.9%, $n=79$) reported that they had made healthcare decisions for others. An ANOVA was performed to examine the relationship between the engagement score and making healthcare decisions for others. The ANOVA showed that there was not a statistically significant association between the independent variable making healthcare decisions for others and the engagement score, $F(1, 187) = 1.537$, $p = 0.22$.

Question 2G: What is the strength of the association between engagement in advance care planning and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, religion, and health literacy?

An ANOVA was performed to examine the relationship between the engagement score and the sociodemographic variables of age, gender, ethnicity, marital status, income, education, religion, and health literacy. The independent variables were isolated to determine which were statistically significant predictors. Age, gender, ethnicity, marital status, education, and income were all found to have a statistically significant

association with engagement score. The ANOVA showed that there was no significant association between engagement score and religion or between engagement score and health literacy.

Data showed a statistically significant association between engagement score and age, $F(3,185) = 4.978$, $p < .01$, indicating that age is a variable that affects engagement in ACP. Post hoc analyses were performed using Tukey HSD, which indicated statistically significant differences between the age group of over 70 and the age groups of 51–60 and 61–70. Participants over age 70 had significantly higher engagement scores ($M = 131.6$, $SD = 18.165$) than those between the ages of 51–60 ($M = 107.22$, $SD = 46.302$) and the ages of 61–70 ($M = 114.4$, $SD = 38.726$).

A statistically significant association was also found between engagement score and gender, $F(1,187) = 5.308$, $p < .05$, indicating that gender is a variable that affects engagement in ACP. Men had significantly higher engagement scores ($M = 128.54$, $SD = 32.087$) than women ($M = 116.7$, $SD = 38.192$) in this study.

There was also a statistically significant association between engagement score and ethnicity, $F(2,186) = 3.439$, $p < .05$, indicating that ethnicity is a variable that affects engagement in ACP. Post hoc analyses were performed using Tukey HSD. Statistically significant differences were found between Asians and African-Americans, with Asians having higher engagement scores ($M = 147.38$, $SD = 27.448$) than African-Americans ($M = 115.97$, $SD = 37.407$). However, only 8 participants identified as Asian.

Statistically significant associations were also found between engagement score and marital status, $F(3,185) = 6.9$, $p < .01$. This indicates that marital status is a variable that affects engagement in ACP. Post hoc analyses were performed using Tukey HSD.

Statistically significant differences were found between the group of participants who were divorced and all other participants. Participants who were divorced had significantly lower engagement scores ($M = 97.86, SD = 50.826$) than those who were single ($M = 117.53, SD = 32.434$), married ($M = 129.1, SD = 30.399$), or widowed ($M = 129.43, SD = 27.194$).

Education level was also found to be a variable that affects engagement in ACP, $F(9,176) = 12.531, p < .01$. Post hoc analyses were performed using Tukey HSD.

Statistically significant differences were found between several groups. The group of participants who reported high school as the highest level of education had significantly lower engagement scores ($M = 79.74, SD = 38.871$) than those who reported education levels of vocational school ($M = 116.5, SD = 15.0$), some college ($M = 128.4, SD = 25.452$), bachelor degree ($M = 128.8, SD = 12.669$), master's degree ($M = 144.16, SD = 22.816$), doctoral degree ($M = 167.0, SD = 0$), and professional degree ($M = 137.3, SD = 44.397$). Those who reported some college ($M = 128.4, SD = 25.452$) or bachelor degrees ($M = 128.8, SD = 12.669$) had engagement scores significantly lower than those with either master's ($M = 144.16, SD = 22.816$) or doctoral degrees ($M = 167.0, SD = 0$).

Self-reported income level was also found to be a variable that affects engagement in ACP, $F(6,179) = 4.735, p < .01$. Post hoc analyses were performed using Tukey HSD. Statistically significant differences were found between the income level of \$75,000–\$99,999 ($M = 139.41, SD = 24.683$) and the levels of \$25,000–\$49,999 ($M = 107.59, SD = 37.25$) and \$50,000–\$74,999 ($M = 104.71, SD = 45.088$). Statistically significant differences were also found between those declining to answer and the levels of \$25,000–\$49,999 ($M = 107.59, SD = 37.25$) and \$50,000–\$74,999 ($M = 104.71, SD =$

45.088). There were also statistically significant differences between those declining to answer ($M = 135.7, SD = 28.815$) and those with income levels of \$25,000–\$49,999 ($M = 107.59, SD = 37.25$) and \$50,000–\$74,999 ($M = 104.71, SD = 45.088$).

In summary, this study demonstrates that comorbidity, age, gender, ethnicity, marital status, education, and income are all factors that are associated with engagement in ACP as measured by the ACPES. Heart failure stage and class were not found to have statistically significant associations with engagement in ACP; nor were recent hospitalizations or making healthcare decisions for others.

CHAPTER 5

DISCUSSION

This was the first study to examine the impact of heart failure stage/class, comorbidities, recent hospitalizations, participant perception of health status, making healthcare decisions for others, and demographic variables on engagement in advance care planning (ACP). Specifically, the purpose of this study was to determine the association between these variables and engagement in ACP, as measured by the Advance Care Planning Engagement Survey (ACPES). This chapter reviews the findings of the current study and discusses how the findings support and advance the current science related to ACP. Recommendations for practice and future research as well as study limitations are also described.

Main Findings

Although the main hypothesis of this study was that heart failure stage or class would be associated with engagement in ACP, the findings did not support it. Findings from this study indicate that there are no significant associations between heart failure class or stage, recent hospitalizations, making healthcare decisions for others, or how a patient rated how they were feeling, and engagement in ACP. However, comorbidity, as measured by the Charlson Comorbidity Index (CCI), was significantly associated with engagement in ACP in this study. Among demographic variables, age, gender, marital status, and education level were also significant predictors of engagement in ACP.

Heart Failure Stage/Class and Advance Care Planning Engagement

Prior to this study, the association between of heart failure stage or class and engagement in ACP was unknown. It was originally hypothesized that heart failure stage

and class would help to predict engagement in ACP because as the disease progresses, patients have more deleterious symptoms and have a poorer prognosis. The likelihood of mortality from heart failure increases as a patient progresses through the stages, as do patient symptoms, because of irreversible changes to the heart structure. Similarly, patient symptoms are assessed through heart failure class, and patient progression through the classes indicates that patients are more likely to have symptoms that negatively impact their quality of life, including shortness of breath and inability to perform normal daily activities. However, we found no association between heart failure stage or class and engagement in ACP. One possibility for this lack of association is that the cardiology practice routinely discussed advance care planning with patients.

Comorbid Conditions' Effect on Advance Care Planning Engagement

This study demonstrated that comorbid conditions, as measured by the CCI, were a statistically significant predictor of engagement in ACP as measured by the ACPES. In practical terms, the study showed that a patient's overall health (as measured by the presence of comorbidities), may be a way to determine a patient's level of engagement in ACP; the greater the number of comorbidities, the more engaged the patient is likely to be in ACP. This is significant because comorbidities are found within the medical record and can be easily identified to help target patients who may be ready to receive interventions on ACP. With electronic medical records, the presence of certain comorbid conditions could trigger alerts to prompt the delivery of certain interventions. For instance, this study indicates that people with multiple comorbid conditions are more likely to be at a higher level of engagement, and thus further along the stages of change, with regard to ACP. Those with fewer, or no, comorbid conditions, are less likely to be

engaged in ACP, and thus would be in earlier stages of the TTM, such as pre-contemplation.

This finding is consistent with the existing literature, which indicates that patients with higher numbers of comorbid conditions are more likely to have ACP documented in their medical records, especially those with heart failure or chronic obstructive pulmonary disease (COPD) (Bond et al., 2018). Other studies have shown that the odds of ACP documentation, consisting of either advance directives or discussions of care goals, increased with the presence of comorbid chronic illnesses such as heart disease, diabetes, and cancer (De Gendt, Bilsen, Stichele, and Deliens, 2013; Hash, Bodnar-Deren, Leventhal, and Leventhal, 2016; Meeusen et al., 2011). These studies, however, examine only the action phase of ACP, and thus cannot be directly compared.

In contrast, Barkley and colleagues (2018) found no significant association between CCI and ACP status when retroactively reviewing medical records. Documentation of ACP status in that study was limited to having an advance directive in the medical record, having discussion of it in progress notes, or having no ACP information at all. This limited assessment of medical records examined only the action stage of ACP, which could be the reason for the contradictory results; patients may not have provided advance directives and the providers may not have noted discussions in the progress notes. Additionally, the study examined only the end result of the ACP process rather than examining engagement as a whole.

Similarly, David et al. (2018) found that lower CCI levels were associated with higher engagement scores on the ACPES. However, one reason for the discrepancy between the findings of our research and the David et al., study is that David et al. used a

shortened form of the CCI, with only five intervals ranging from no comorbidity to severe comorbidity. Our research used the original CCI as ratio data with a range from zero to twenty-eight points, and the majority of the participants had CCI scores over four. The comorbidity scoring was thus more specific than the dichotomous division used by David et al. Additionally, the patient populations are different, as the participants in David's research had to have had at least two chronic conditions and had either an emergency room visit or hospital admission within the previous year to qualify for the study. Our research also includes participants that have no comorbid conditions other than heart failure, or a precursor to it. These variables may have impacted David's results, making it less comparable to the current study.

Recent Hospitalizations

Howard et al. (2016) recruited patients from a hospital, cancer care center, dialysis care center, and primary care clinics and found that the currently hospitalized patients had the highest scores on the ACPES, which is unsurprising given that patients are asked if they want to complete advance directive documents upon hospital admission. Our study recruited patients in the community and hospitalization data was based on a recall of experiences over the past two years. Approximately one-half of the survey responders reported that they had been hospitalized in the previous two years, but this experience was not found to be significantly associated with engagement in ACP. This lack of association could indicate that the impact of being asked about advance directives and surrogate decision-makers upon admission to a hospital does not extend beyond the hospitalization itself.

Making Healthcare Decisions for Others

There is minimal information available about the impact of making healthcare decisions for others on a person's own engagement in ACP. Prior research has shown that the serious illness of a family member or friend prompts people to pursue advance care planning for themselves, but did not specify whether this was necessarily in response to making decisions for that person (Levi, Dellasega, Whitehead, & Green, 2010; van Wijmen, Pasman, Widdershoven, & Onwuteaka-Philipsen, 2014). The hypothesis that there would be an association between the two variables was based upon the conceptual theory on stages of change, which describes information as the impetus for moving from the precontemplation stage to the contemplation stage. It followed that experience being a surrogate decision-maker would result in people being more engaged in their own ACP, but the current study found no significant association between these two variables. It is possible that age factors into this variable, as those who are older will be more likely to have experienced a friend or family member dying from a serious illness. The majority of participants in the current study were over age 60. A better way to assess this variable may have been to ask about experiences with friends or family dying after a prolonged serious illness rather than asking about making the decisions for others.

Patient Perception of Health Status

Patient perception of health status was assessed using three different strategies, but only one was statistically significant. Participant rating of their health status compared to one year prior was significantly associated with engagement in ACP, but the post hoc analyses indicate that those who considered their current health *worse* than one

year prior were actually less engaged in ACP than those who considered it *about the same*.

When looking at rating their health at the present time, other studies found that those who considered themselves healthy were less likely to be engaged in ACP than those who did not (Hash et al., 2016; Howard, et al., 2016; Inoue, 2016; Tripken, J. L., Elrod, C., & Bills, S., 2016), but in the current study, this perception of health status was not statistically significant.

Finally, this study examined how a patient was currently feeling to see if there was an association between that and engagement in ACP. No research on this particular topic could be located, but in preparatory work, participants indicated that how they were feeling that day would change their answers to some of the ACPES questions. This hypothesis was not supported by study findings.

Sociodemographic Variables and Engagement in ACP

Age, gender, marital status, education, and income. This study also examined a number of sociodemographic variables to determine their association with ACP. Age, gender, marital status, education, and income were all found to be significant predictors of engagement in ACP. Increasing age increased engagement in ACP, which is consistent with prior research (Boucher, 2017; Dow et al., 2010; Fried et al., 2010; Inoue, 2016; Reynolds, Hanson, Henderson, & Steinhauser, 2008). Gender was also associated with engagement in ACP, with men having greater engagement scores than women in this study. Prior research has mixed results in this area, with some finding men to be more engaged (Fried et al., 2010), some finding women to be more engaged (Boerner, Carr, & Moorman, 2016; Inoue, 2016), and some finding that gender did not affect ACP

(Sudore et al., 2008). Those who were married also had higher rates of ACP, which is again consistent with prior research (Boerner, Carr & Moorman, 2013; Fried et al, 2010; Koss, 2017).

Education level was a strong predictor of engagement in ACP, with higher education levels increasing engagement; this was consistent with prior research (Bullock, 2011; Doyle, 2016; Muessen et al., 2011; Pereira-Salgado, Mader, & Boyd, 2018; Wagner et al., 2010). Higher total household income levels were also associated with higher engagement scores in the current study, which is consistent with prior research (Alano et al., 2010; Dobalian, 2006; Doyle, 2016; Khosla, Curl, & Washington, 2016; Moorman & Inoue, 2013; Pollack et al., 2010). One surprising finding in this study was that those in the lowest income bracket (less than \$25,000 annually) had the second-highest levels of engagement in ACP; this is inconsistent with prior research, and could be due to some of the study limitations discussed in chapter five.

Ethnicity. Ethnicity was found to be a statistically significant predictor of engagement, but post-hoc results indicated that this was significant only between participants identifying as African-American or Asian. Because only eight participants identified as Asian, the sample size is likely too small to generalize this finding. There were no differences between African-Americans and Caucasians, a finding that is inconsistent with prior research. Multiple studies have examined the effects of ethnicity on rates of ACP and have shown that in general, ethnic minorities have lower rates of ACP than Caucasians (Bullock, 2011; Carr, 2011; Dow et al., 2010; Guo et al., 2010; Huang, 2016; Reynolds et al., 2008). Hypothesized reasons for these lower levels of ACP include lack of trust in the healthcare system, a focus on religiosity/spirituality,

disparities in communication about ACP and EOL care, and reliance on family members to make the “right” decisions (Carr, 2012; Car & Luth, 2017; McAfee, Jordan, Sheu, Dake, & Kopp Miller, 2017; Smith, McCarthy, Paulk, Balboni, Maciejewski, Block, & Prigerson, 2008). In the current study, where there was no significant difference between Caucasians and African-Americans, it is likely that the results were skewed because of a standard practice of discussing ACP on at least an annual basis with every patient (see discussion in chapter five on limitations).

Religious preference. Religious preference was not found to be a statistically significant predictor of engagement in the current study. Prior research has shown that religiosity/spirituality has an impact on specific ACP behaviors such as living wills and appointing a surrogate decision-maker (Garrido, Idler, Leventhal, & Carr, 2013; Janssen et al., 2016), but the current study assessed only religious preference rather than religiosity/spirituality. Additionally, the sample was largely homogeneous, with 85% of the participants identifying as Christian, which may have impacted any differences. While only ten participants elected not to answer, their mean ACPES score was significantly lower than that of those identifying with a particular religion. Larger, less homogeneous samples may be more consistent with other research.

Documentation: Surrogate Decision-Makers and Advance Directives

The majority of patients (59.7%) in this study reported that they have formally asked someone to be a surrogate decision-maker (SDM) for healthcare decisions and 97% of those people had signed official documentation. The majority of patients (56.9%) also reported having completed advance directives. This is a much higher percentage than in the general population, where recent statistics show that 37% of people have completed

advance directives (Yadav et al., 2017). Percentages of heart failure patients with advance directives range from 12.7% (Butler et al., 2015) to 41% (Dunlay, Swetz, Mueller, & Roger, 2012), but these results are somewhat dated. More recently, Yadav et al. (2017) found that 38.2% of adults with chronic illnesses had completed advance directives, as opposed to only 32.7% of healthy adults. When divided into type of advance directive, Yadav noted that 33.4% of all patients had appointed a surrogate decision-maker. The current study again shows a significantly higher percentage of completion of advance directives than the literature shows. Rather than conflicting with current literature, the higher percentage is likely reflective of the cardiology practice, as advance care planning was routinely discussed during patient appointments.

Summary

Overall, the data from this study show that while heart failure stage and class were not significant predictors of engagement in ACP, comorbid conditions, quantified in the CCI, are significantly associated with engagement in ACP, with higher engagement seen in those with higher CCIs. Certain demographic variables were found to be significantly associated as well, largely consistent with the literature, with some discrepancies that may be due to the limitations of this study.

Implications for Practice

The main hypothesis of this study was that heart failure stage or class would be predictive of engagement in ACP, and the data here did not support that, but there were a number of possible reasons for this, primarily that the cardiology practice routinely discussed advance care planning with patients. Results do show that engagement may be able to be predicted by the presence of comorbidities, especially chronic and terminal

diseases. Understanding where a patient may be on the stage of change continuum can help determine which type of intervention may be best received by the patient with regard to increasing ACP engagement. Because the ACPES was developed based partly on the stages of change, higher levels of engagement generally reflect stages of change further along the continuum. Thus, if a patient is determined to have a low score, he is likely to be in one of the earlier stages of change. Because it would not be feasible to administer the ACPES to every patient, variables that are significant predictors of engagement can be a substitute for the engagement score. Variables based on data that are easily located within the medical records, such as comorbid conditions, can be used to trigger practice alerts. For example, an alert can be triggered for any patient diagnosed with a terminal illness such as heart failure or renal failure, or for patients with a certain number of chronic diseases that are not necessarily terminal. Recently, researchers developed a Best Practice Alert that was triggered by the presence of Stage IV cancer (Pandya, An, Duberstein, Dougherty, & Smith Noel, 2018). The Alert notified providers to discuss Medical Orders for Life Sustaining Treatment (MOLST). Results showed a significant increase in the discussion of ACP, including MOLST and palliative care referrals.

In practice, healthcare providers should continue to discuss ACP with patients, but the interventions should be targeted toward engagement levels. A patient with very few comorbidities is less likely to be engaged in ACP, and thus should receive interventions that are intended to familiarize the patient with ACP in general, rather than interventions where the end goal is a discussion of end-of-life. At the opposite end of the spectrum, patients with high numbers of comorbidities are likely to be more engaged in the process and thus will be more receptive to interventions that are more specific and

aimed at the patient making decisions about healthcare goals. Findings from this study indicate that targeted interventions for advance care planning may be more effective if based on presence of comorbid conditions and demographics rather than on stage of heart failure.

Future Research

There are many areas where ACP research is needed and can be expanded. When specifically looking to the ACPES, research is needed to determine its validity in a variety of populations, including those who are younger and those without chronic health conditions. A review of the literature shows that it has been tested only in populations aged 50 or older (Howard et al., 2016; Sudore et al., 2013). Additionally, the survey is lengthy and would be cumbersome to administer on a routine basis. Recent efforts to validate a shortened survey, however, indicate that reducing the number of questions to as little as four may still result in adequate assessment of engagement in ACP (Sudore et al., 2017). A four-question survey is much more feasible to administer, especially to people with chronic health conditions.

Future research is also needed to develop interventions that are targeted for certain groups of individuals. The current study was aimed at one of the first steps in this process: identifying factors that affect a person's level of engagement in ACP. Understanding someone's readiness to engage in the ACP process will lead to better identification of the stage of change that person is in as related to ACP. At that point, interventions should be targeted based on the stage of change, rather than a "one size fits all" intervention. Someone who is early in the stages, such as pre-contemplation, will need a different intervention than someone who is in the later stages such as action

(Zimmerman, Olsen, & Bosworth, 2000). Fried's work (2010), however, noted that someone may be in different stages of change for different ACP behaviors, and this would require different interventions for each behavior, which would make it difficult to address via different interventions. As an example, someone may be in the action phase for discussing their values and preferences with family and friends, but in pre-contemplation for discussing it with their providers.

Lum and colleagues (2018) recently developed a successful intervention designed to improve the full range ACP behaviors. The PREPARE website uses videos and other behavior change techniques to address knowledge, contemplation, self-efficacy, and readiness with regard to all four of the domains of the ACP process (decision makers, quality of life, flexibility in surrogate decision making, and asking clinicians questions). The study also used an easy-to-read AD in order to help people complete documentation of their wishes. A control group used only the easy-to-read AD. While both interventions increased ACP, the PREPARE intervention resulted in nearly 100% engagement in the full range of ACP behaviors, including discussions with family and providers and documentation.

With regard to the differences seen in ethnicity, future research is needed to narrow the gap seen in engagement. It has been theorized that this may be partially due to access to healthcare and trust in the system. Regardless of the cause, there should be no disparities in ACP engagement based on ethnicity. Recent research indicates that African-Americans may prefer informal conversations about ACP rather than the use of formal ADs (Carr, 2011; Gerst & Burr, 2008; Johnson, Tuchibhatla, & Tulsky, 2008;

Teno et al., 1997). Based on this, some interventions are now being carried out jointly with churches and other faith communities (Carr & Luth, 2017).

Study Limitations

An important limitation of the current study is the low response rate of patients with Stage D heart failure, resulting in the need to combine their results with those of patients with Stage C heart failure. Study findings may not be fully representative of all stages of heart failure due to difficulty identifying patients in Stage A and the low response rate from patients in Stage D. Although the current study showed that heart failure stage and class were not statistically significant predictors of engagement, the results could change if the sample size were larger and more diverse.

A greater percentage of participants identified as White or Caucasian than African-American (56.2% and 39%, respectively). In the general population, however, African-Americans are 1.5 times more likely to develop heart failure. This discrepancy may be reflective of the cardiology practice, but race/ethnicity of the non-responders was not collected.

Another limitation is that the participants were all recruited from one group of cardiologists in Cincinnati, Ohio, and may not represent the general population of patients with heart failure. Additionally, the physicians at this practice routinely discussed advance care planning during their appointments with patients, thus potentially skewing the results. The current study, having found no significant differences in engagement in ACP between Caucasians and African-Americans, was inconsistent with previous literature, which indicates that African-Americans are generally less engaged in ACP than Caucasians (Bullock, 2011; Carr, 2011; Dow et al., 2010; Guo et al., 2010;

Huang, 2016; Reynolds et al., 2008). This may be due to the restricted sample coming from only one heart failure physician group. Additionally, the physicians at the group routinely discussed ACP during patient office visits, which may have confounded any difference based on race/ethnicity in the current results.

The modified ACPES used in this study is new and not widely used. The participants in the original research were over 55 years of age with at least two chronic medical conditions, and later testing of the survey was also done on patients aged 50 or older (Howard et al., 2016). Recent work has been aimed at making the survey more feasible to administer, while retaining its validity. The ACPES was examined as 82, 55, 34, 15, nine, and four items (Sudore et al., 2017). The 55-, 34-, and 15-item modifications were found to have internal consistency and construct validity similar to the 82-item survey. The smallest surveys, of nine and four items, were recommended for use in quality improvement settings or in clinical studies with limited resources.

Conclusion

This study provides preliminary evidence demonstrating that the extent of a patient's comorbidities is associated with stage of engagement in ACP. Because the rates of ACP remain low despite an increased movement to address them, interventions are still needed to improve ACP among a variety of populations, including both healthy adults and those with chronic illnesses. This study is the first step to developing such interventions, by identifying variables that can be used to predict a person's level of engagement and stage of change, and thus develop interventions targeted at moving someone along the change continuum.

APPENDIX A: INTRODUCTION LETTER



This letter is to introduce Lori Catalano, RN, who is a doctoral student in the School of Nursing at Indiana University and has worked with me in the past. She is working with me and Dr. Susan Hickman, her advisor, doing research on advance care planning. We would like to invite you to assist with this project by completing two questionnaires which cover certain aspects of this topic. The questionnaires should only take about 10 minutes for you to complete.

Advance care planning is making decisions about the care you would want to receive if you become unable to speak for yourself. Your decisions are based on your personal values, preferences, and discussions with your loved ones. It includes talking about your goals and preferences for care with your family and loved ones and your healthcare providers. It also includes completing official documentation, including the appointment of a healthcare proxy or surrogate decision maker, and the completion of living wills or advance directives. Additional resources about advance care planning are provided in this packet should you wish to explore them after completing the questionnaires.

For this study, you will be asked to complete two questionnaires. The first one contains questions about your background. The second contains questions about advance care planning. Your participation is voluntary and you may skip any question that you do not want to answer. When you complete the questionnaires, please place them in the provided postage-paid envelope and return them through U.S. mail.

While there are no direct benefits to you for participating in this study, your participation is greatly appreciated. As a token of appreciation, if you return the questionnaires within the first two weeks, you will be entered into a drawing for three \$50 gift cards to a local grocer of your choice. If you return the questionnaires after the first two weeks, you will be entered into a drawing for three \$25 gift cards to a local grocer of your choice. If you do not return the questionnaires within one month, your information will not be able to be included in the research. To be entered in the drawing, fill out your name, address, telephone number, and preferred grocer on the provided index card and include it in the envelope when you return it.

Be assured that any information provided will be treated in the strictest confidence and you will never be identified by name in any publication or presentation. If you have any questions about this study, please call Lori Catalano, at xxx-xxx-xxxx, or Dr. Susan Hickman at xxx-xxx-xxxx.

Information about HIPAA

By returning the survey and question, you are giving permission for your PHI (Protected Health Information) to be released from Ohio Heart & Vascular Center to the research team, for the specific purpose of this study. You have the right to decide who may review or use your PHI. For this study, the research team will have access to your name, address, birthdate, and medical record number.

This permission is for the research team to access your medical records to determine your medical history, including your heart failure stage and other medical diagnoses. No other information will be accessed from your medical records, and the information will be used only for this research study.

You are giving permission for the following people to access your PHI for the purposes of this study:

- The researchers and research staff conducting the study at Indiana University and IU Health
- Principal Investigators: Susan Hickman, Lori Catalano, and Santosh Menon
- The members and staff of the Human Subjects Office
- The members of the Institutional Review Boards (IRB) that approve this study
- Indiana University and/or Indiana University affiliated institutions with compliance and financial oversight, including but not limited to the Office of Research Compliance, Office of Research Administration, HIPAA Privacy and Security Compliance Office, General Counsel's Office, Internal Audit, and US or foreign governments or agencies as required by law

Efforts will be made to ensure that your PHI will not be shared with other people outside of the research study. However, your PHI may be disclosed to others as required by law and/or to individuals or organizations that oversee the conduct of research studies, and these individuals or organizations may not be held to the same legal privacy standards as are doctors and hospitals. Thus, the Research Team cannot guarantee absolute confidentiality and privacy.

You have the right to not return the surveys. If you do not return the surveys to the research team, then your medical history will not be shared. Not signing the form will not affect my regular health care including treatment, payment, or enrollment in a health plan or eligibility for health care benefits. However, not signing the form will prevent me from participating in the research study above. You also have the right to review and obtain a copy of my personal health information collected during the study. However, it may be important to the success and integrity of the study that persons who participate in the study not be given access until the study is complete. The Principal Investigator has discretion to refuse to grant access to this information if it will affect the integrity of the study data during the course of the study. Therefore, your request for information may be delayed until the study is complete. You may also cancel this authorization at any time. To do so, you must notify the Principal Investigator (Lori Catalano) for this study in writing at: University of Cincinnati College of Nursing, P.O. Box 210038, Cincinnati,

OH, 45221-0038. If you cancel this authorization, the Research Team may still use information that was collected as part of the research project from the time you returned the survey to the date you cancel the authorization. This is to protect the quality of the research results.

APPENDIX B: BACKGROUND QUESTIONNAIRE



INDIANA UNIVERSITY

Advance Care Planning Engagement Survey

BACKGROUND QUESTIONNAIRE

1. What is your age?
 - a. 18 – 30
 - b. 31 – 40
 - c. 41 – 50
 - d. 51 – 60
 - e. 61 – 70
 - f. Over 70

2. What is your gender?
 - a. Male
 - b. Female

3. What is your race? Circle all that apply.
 - a. African American or black
 - b. Caucasian or white
 - c. Asian
 - d. American Indian / Native Alaskan
 - e. Native Hawaiian or other Pacific Islander
 - f. Decline to answer
 - g. Unknown

4. Would you consider yourself to be Hispanic or Latino?
 - a. Yes, Hispanic or Latino
 - b. No, not Hispanic or Latino
 - c. Decline to answer
 - d. Unknown

5. What is your current marital status?
 - a. Single
 - b. Married
 - c. Widower or widowed
 - d. Divorced
 - e. Living with partner
 - f. Decline to answer

6. When you consider your total household income, would you say that you are comfortable, have just enough to make ends meet, or do NOT have enough to make ends meet?
 - a. Comfortable
 - b. Just enough to make ends meet
 - c. Do not have enough to make ends meet

7. How much is your total annual household income before taxes?
 - a. Under \$24,999
 - b. \$25,000 – \$49,999
 - c. \$50,000 – \$74,999
 - d. \$75,000 – \$99,999
 - e. Over \$100,000
 - f. Unknown
 - g. Decline to answer

8. What is the highest level of education you have completed?
 - a. Grammar school
 - b. High school or equivalent (GED)
 - c. Vocational/technical school (2 year)
 - d. Some college
 - e. Bachelor degree
 - f. Master's degree
 - g. Doctoral degree
 - h. Professional degree (JD, MD, etc.)
 - i. Other
 - j. Decline to answer

9. Which of the following best describes where you live?
 - a. Urban
 - b. Suburban
 - c. Rural

10. What is your religious preference?
 - a. Protestant
 - b. Catholic
 - c. Other Christian
 - d. Mormon
 - e. Jewish
 - f. Muslim
 - g. Other non-Christian religion
 - h. Prefer not to answer
 - i. No religion

11. In general, would you say your health is:
 - a. Excellent
 - b. Very good
 - c. Good
 - d. Fair
 - e. Poor

12. How do you prefer to make your healthcare decisions?
 - a. All on your own
 - b. With input from friends and family
 - c. Shared decision making with doctor or other provider
 - d. Have doctor make decisions for you

13. How confident are you filling out medical forms?
 - a. Excellent
 - b. Very good
 - c. Good
 - d. Fair
 - e. Poor

14. How often do you have problems learning about your medical condition because of difficulty understanding written information?
 - a. Almost all of the time
 - b. Frequently
 - c. Occasionally
 - d. Rarely
 - e. Never

15. How often do you have someone help you read hospital materials?
 - a. Almost all of the time
 - b. Frequently
 - c. Occasionally
 - d. Rarely
 - e. Never

16. Have you already formally asked someone to be your medical decision maker?
 - a. Yes
 - b. No

17. Have you signed official papers naming a person or group to make medical decisions for you?
 - a. Yes
 - b. No

18. If you have already asked someone to be your medical decision maker, have you talked with him/her about whether certain health situations would make your life not worth living?
 - a. Yes
 - b. No
 - c. I have not asked someone to be my decision maker

19. If you have already asked someone to be your medical decision maker, have you talked to him/her about how much flexibility you want to give her/him?
 - a. Yes
 - b. No
 - c. I have not asked someone to be my decision maker

20. Have you signed official papers to put your wishes about how much flexibility to give your decision maker in writing?
 - a. Yes
 - b. No
 - c. I have not asked someone to be my decision maker

21. Have you talked to your doctor about who you want your medical decision maker to be?
 - a. Yes
 - b. No

22. Have you talked with your doctor about whether certain health situations would make your life not worth living?
 - a. Yes
 - b. No

23. Have you signed official papers about your wishes for medical care if you were seriously ill or dying (known as a living will or advance directive)?
 - a. Yes
 - b. No

APPENDIX C: ADVANCE CARE PLANNING ENGAGEMENT SURVEY

Advance Care Planning Engagement Survey

Please answer the following questions based on how you feel today.

1. How well informed are you about what makes someone a good decision maker?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

2. How well informed are you about the types of decisions that a medical decision maker may have to make for you in the future?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

3. How much have you thought about who you think your medical decision maker should be?
 - a. Never
 - b. Once
 - c. A few times
 - d. Several times
 - e. A lot

4. How confident are you that today you could ask someone to be your medical decision maker?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

5. How confident are you that today you could talk with your doctor about who you want your medical decision maker to be?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

6. How confident are you that today you could talk with your other family and friends about who you want your medical decision maker to be?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

7. How ready are you to formally ask someone to be your medical decision maker?
 - a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

8. How ready are you to talk with your doctor about who you want your medical decision maker to be?
 - a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

9. How ready are you to talk to your other family and friends about who you want your medical decision maker to be?
 - a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

10. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?
 - a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

11. How confident are you that today you could talk with your medical decision maker about whether or not certain health situations would make your life not worth living?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

12. How confident are you that today you could talk with your doctor about whether or not certain health situations would make your life not worth living?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

13. How confident are you that today you could talk with your other family and friends about whether or not certain health situations would make your life not worth living?
 - a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely

14. How ready are you to decide whether or not certain health situations would make your life not worth living?
 - a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

15. How ready are you to talk to your decision maker about whether or not certain health situations would make your life not worth living?
 - a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

16. How ready are you to talk to your doctor about whether or not certain health situations would make your life not worth living?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it
17. How ready are you to talk to your other family and friends about whether or not certain health situations would make your life not worth living?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it
18. How much have you thought about talking with your other family and friends about the care you would want if you were very sick or near the end of life?
- Never
 - Once
 - A few times
 - Several times
 - A lot
19. How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?
- Not at all
 - A little
 - Somewhat
 - Fairly
 - Extremely
20. How confident are you that today you could talk with your doctor about the care you would want if you were very sick or near the end of life?
- Not at all
 - A little
 - Somewhat
 - Fairly
 - Extremely

21. How confident are you that today you could talk with your other family and friends about the care you would want if you were very sick or near the end of life?
- Not at all
 - A little
 - Somewhat
 - Fairly
 - Extremely
22. How ready are you to decide on the medical care you would want if you were very sick or near the end of life?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it
23. How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it
24. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it
25. How ready are you to talk to your other family and friends about the kind of medical care you would want if you were very sick or near the end of life?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it

26. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it
27. How much have you thought about talking with your medical decision maker about how much flexibility you want to give them?
- Never
 - Once
 - A few times
 - Several times
 - A lot
28. How confident are you that today you could talk with your doctor about how much flexibility you want to give your medical decision maker?
- Not at all
 - A little
 - Somewhat
 - Fairly
 - Extremely
29. How confident are you that today you could talk with your other family and friends about how much flexibility you want to give your medical decision maker?
- Not at all
 - A little
 - Somewhat
 - Fairly
 - Extremely
30. How ready are you to talk to your decision maker about how much flexibility you want to give them?
- I have never thought about it
 - I have thought about it, but I am not ready to do it
 - I am thinking about doing it in the next 6 months
 - I am definitely planning to do it in the next 30 days
 - I have already done it

31. How ready are you to talk to your doctor about how much flexibility you want to give your decision maker?
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it
32. How ready are you to sign official papers putting your wishes in writing about how much flexibility to give your decision maker?
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it
33. How confident are you that today you could ask the right questions of your doctor to help make good medical decisions?
- a. Not at all
 - b. A little
 - c. Somewhat
 - d. Fairly
 - e. Extremely
34. How ready are you to ask your doctor questions to help you make a good medical decision?
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it

Please add any other information you feel is important below:

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Curriculum Vitae

Lori A. Catalano

FORMAL EDUCATION

2019, PhD, Indiana University School of Nursing

2011, MSN, University of Cincinnati College of Nursing

2006, JD, Capital University Law School

1999, BSN, University of Cincinnati College of Nursing

PROFESSIONAL REGISTRATION & CERTIFICATIONS

Registered Nurse (RN), State of Ohio, 07/1999 to present

Progressive Care Certified Nurse (PCCN), American Association of Critical-Care Nurses, 2009 to present

Critical-Care Clinical Nurse Specialist (CCNS), American Association of Critical-Care Nurses, 2012 to present

PROFESSIONAL EXPERIENCE

<i>Position</i>	<i>Institution</i>	<i>Location</i>	<i>Dates of Employment</i>
Assistant Professor of Clinical Nursing	University of Cincinnati College of Nursing	Cincinnati, Ohio	August 2013 to present
	<ol style="list-style-type: none">1. Direct supervision and evaluation of students in the clinical arena and in the skills laboratories2. Facilitation of simulated lab experiences3. Development of content to meet course objectives and college goals using a variety of active learning strategies4. Provision of in-class didactic instruction and development of testing scenarios5. Provision of online didactic instruction		

Visiting Assistant Professor of Clinical Nursing	University of Cincinnati College of Nursing	Cincinnati, Ohio	January 2011 to August 2013
	<ol style="list-style-type: none"> 1. Direct supervision and evaluation of students in the clinical arena and in the skills laboratories 2. Facilitation of simulated lab experiences 3. Development of content to meet course objectives and college goals using a variety of active learning strategies 4. Provision of in-class didactic instruction and development of testing scenarios 5. Provision of online didactic instruction 		
Content Reviewer	Elsevier Health Sciences	Maryland Heights, Missouri	February 2012 to present
	<ol style="list-style-type: none"> 1. Review of fundamental nursing content for accuracy and consistency 2. Addition of evidence-based resources to nursing textbooks 		
Clinical Instructor	The Christ College of Nursing and Health Sciences	Cincinnati, Ohio	August 2011 to December 2011
	<ol style="list-style-type: none"> 1. Direct supervision and evaluation of students in the clinical arena and in the skills laboratories 2. Facilitation of simulated lab experiences 		

AWARDS/HONORS

Jonas Nurse Leader Scholars Program, Indiana University, 2014–2017

University Fellowship, Indiana University, 2013–2017

Sigma Theta Tau International, Alpha Chapter

Sigma Theta Tau International, Beta Iota Chapter

PUBLICATIONS

Articles, Peer-Reviewed

Catalano, L. A. & Werdman, E. (2018). Avoiding legal risks in critical care nursing. *Nursing 2017 Critical Care*, 12(4), 30–35.

Gaspar, P., Gaspar, T., & Catalano, L. (2016). Establishing a collaboration contract to facilitate team performance. *Doctoral Nursing Practice*, 9(1).

Catalano, L. (2014). What you need to know about electronic documentation. *American Nurse Today*, 9(11), 24, 46.

Catalano, L. (2014). Avoiding copyright violations in educational presentations. *American Nurse Today*, 9(5), 53–54.

Catalano, L. (2006). Totalitarianism in public schools: Enforcing a religious and political orthodoxy. *Capital University Law Review*, 34(3), 601–645.

Books

Catalano, L. (2018). Legal implications in nursing practice. In Potter, P. A., Perry, A. G., Stockert, P. A., & Hall, A. *Essentials of Nursing Practice*. (9th ed.). St. Louis, MO: Elsevier.

Catalano, L., Contributing Author: Dennison, R.D. (2015). *Pass PCCN!* St Louis, MO: Mosby-Elsevier.

Catalano, L., Contributing Author: Dennison, R.D. (2013). *Pass CCRN!* (4th ed.). St Louis, MO: Mosby-Elsevier.

PRESENTATIONS

National Presentations

Catalano, L & Werdman, E, *Incorporating Errors into Simulation to Improve Patient Safety*, Poster Presentation, National League of Nursing Annual Education Summit, Chicago, IL, September 2018

Maintaining Student Engagement in the Classroom, Podium Presentation, 2017 iCoN Summer Institute, Cincinnati, Ohio, July 2017

Catalano, L & Werdman, E, *Incorporating Multiple High-Fidelity Simulations and High-Stakes Simulation Assessment into Medical/Surgical and Critical Care Nursing Courses*, Poster Presentation, National League of Nursing Annual Education Summit, Orlando, FL, September 2016

Johnson KD, Catalano, L & Carissimi, K, *The Students Perspectives of the Inclusion of QSEN Competencies for an Informatics Course in an RN-BSN Program*, May 2015, Quality and Safety Education for Nurses National Forum, San Diego, California.

Legal Issues in Professional Nursing, Podium Presentation, September 2013, Progressive Care Pathways, American Association of Critical-Care Nurses, Las Vegas, Nevada

Electronic Health Records, Podium Presentation, September 2013, Progressive Care Pathways, American Association of Critical-Care Nurses, Las Vegas, Nevada

Legal Aspects of Managing, Podium Presentation, September 2013, Nurse Manager Priorities, American Association of Critical-Care Nurses, Las Vegas, Nevada

Intellectual Property Law and Education: Avoiding Copyright Violations, Podium Presentation, May 2013, National Teaching Institute and Critical Care Exposition, American Association of Critical-Care Nurses, Boston, Massachusetts

Malpractice and Other Legal Issues in Professional Nursing, Podium Presentation, May 2013, National Teaching Institute and Critical Care Exposition, American Association of Critical-Care Nurses, Boston, Massachusetts

Intellectual Property Law and Education, Podium Presentation, May 2012, National Teaching Institute and Critical Care Exposition, American Association of Critical-Care Nurses, Orlando, Florida

Legal Issues in Documentation, Podium Presentation, May 2012, National Teaching Institute and Critical Care Exposition, American Association of Critical-Care Nurses, Orlando, Florida

Intellectual Property Law and Education, May 2011, Society for Clinical Nurse Specialist Education Annual Conference, Louisville, Kentucky

Evaluating a Fall Prevention Program Tailored for a Telemetry Unit, Poster Presentation, May 2010, National Teaching Institute and Critical Care Exposition, Washington D.C.

Evaluating a Fall Prevention Program Tailored for a Telemetry Unit, Poster Presentation, October 2009, American Journal of Nursing Annual Conference, Chicago, Illinois

Regional Presentations

Ohio Nursing Law Update – Category A, Podium Presentation, 2019 Forum on Aging, Sharonville, OH, March 2019

Comparing Engagement in Advance Care Planning Between Stages of Heart Failure, Student Poster Presentation, Midwest National Research Society Annual Research Conference, Cleveland, OH, May 2018

Catalano, L & Werdman, E, *Incorporating Multiple High-Fidelity Simulations and High-Stakes Simulation Assessment into Medical/Surgical and Critical Care*

Nursing Courses, Poster Presentation, Ohio League of Nursing, Columbus, OH,
April 2018

Engaging Students Through Technology, Podium Presentation, 2017 University of
Kentucky Faculty Development Conference, Lexington, KY, May 2017

Incorporating High-Stakes Simulation Assessment in Medical/Surgical Courses,
Podium Presentation, 2017 University of Kentucky Faculty Development
Conference, Lexington, KY, May, 2017

Local Presentations

Legal Issues in Nursing: Category A CE, Podium Presentation, June 2017,
University of Cincinnati, Cincinnati, Ohio

Legal Issues in Nursing: Category A CE, Podium Presentation, July 2015,
University of Cincinnati Alumni Council, Cincinnati, Ohio

Intellectual Property Law and Education, Podium Presentation, April 2014,
Trends in Critical Care, American Association of Critical-Care Nurses,
Cincinnati, Ohio

Ensuring Patient Safety by Regulating the Practice of Registered Nurses, May
2011 – August 2011, University Hospital and The Christ Hospital, Cincinnati,
Ohio

Legal Issues in Nursing, May 2011, University Hospital Burn Special Care Unit,
Cincinnati, Ohio

Legal and Ethical Issues in Professional Nursing, May 2011, University of
Cincinnati College of Nursing and Health, Cincinnati, Ohio

Tracheal Tubes and Airway Management, May 2011, University Hospital Burn
Special Care Unit, Cincinnati, Ohio

The Clinical Nurse Specialist: A Facilitator of Learning, Poster Presentation, June
2011, University of Cincinnati College of Nursing and Health, Cincinnati, Ohio

FORMAL TEACHING EXPERIENCE

Courses Developed

University of Cincinnati, Cincinnati, Ohio

2019 NBSN2105 & 2107 Pathophysiology & Pharmacology I & II
2018 NBSN2007 Pharmacology, 3 credit hours, U
2017 NBSN3046 Biomedical Ethics, 3 credit hours, U
2015 PMSN7024C Accelerated Care of Adults, 6 credit hours, U
2014 PMSN7034 Care of Adults with Complex Health Problems I, 3 credit
hours, U
2013 NBSN1001 Introduction to Professional Nursing, 3 credit hours, U
2012 29NURS207 Nursing Ethics and Law, 3 credit hours, U

Courses Taught

University of Cincinnati, Cincinnati, Ohio

2018–2019 NBSN2007: Pharmacology (3U)
2018 NBSN4002C: Care of Adults with Complex Health Concerns (4U)
2017 NBSN3046: Biomedical Ethics (3U)
2016–2018 PMSN7043C: Accelerated Complex CLINICAL (3U)
2015–2018 NBSN2005: Pathophysiology (4U)
2015–2019 NBSN3086: Strategies for NCLEX Preparation (3U)
2014–2019 PMSN7024C: Accelerated Care of Adults (6U)
2014–2017 PMSN7010C: Accelerated Assessment LAB (3U)
2014–2015 PMSN7034: Accelerated Complex I (3U)
2014 NBSN4002C: Care of Adults with Complex Health Concerns CLINICAL
(3U)
2013–2014 NBSN4065: RN-BSN Nurse as Professional Leader/Manager (3U)
2013 PMSN7040C: Accelerated Complex II CLINICAL (3U)
2013 PMSN7024C: Accelerated Care of Adults CLINICAL (3U)
2013 PMSN7012: Accelerated Fundamentals CLINICAL (3U)
2013–2014 PMSN7014: Accelerated Socialization (2U)
2013 NBSN1001: Introduction to Professional Nursing (3U)
2013 NBSN3001C: Care of Adults CLINICAL (3U)
2013, 2015 PMSN7036: Accelerated Leadership (2U)
2012–2015 NBSN2001C: Fundamental Concepts and Skills LAB (2U)
2012–2014 NBSN4064: RN-BSN Genetics (2U)

2012	29NURS203: Foundations of Nursing II CLINICAL (3U)
2012	29NURS202: Foundations of Nursing I (3U)
2012	29NURS207: Nursing Ethics and the Law (3U)
2012	29NURS703: Socialization to Professional Nursing (2U)
2011	29NURS303: Care of Adults CLINICAL (3U)
2011–2012	29NURS700: Accelerated Assessment (2U)
2011	29NURS702: Accelerated Fundamentals of Nursing CLINICAL (3U)
2011	29NURS204: Nursing Health Assessment LAB (2U)
2011–2012	29NURS712: Accelerated Leadership & Management (2U)
2011–2012	29NURS468: RN-BSN Nurse as Professional Leader and Manager (3U)

Christ College of Nursing & Health Sciences, Cincinnati, Ohio
2011 Medical/Surgical CLINICAL (3U)