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Caleb Pardue

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Uncertainty in the Context of End-of-life Communication in Heart Failure

Caleb M. Pardue

M.A., Psychology, University of Missouri-St. Louis, 2015
B.S., Psychology, University of North Carolina-Chapel Hill, 2010

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Advisory Committee

Kamila White, Ph.D.,
Chairperson

Zoë Peterson, Ph.D.

Ann Steffen, Ph.D.

Judith Skala, Ph.D., RN.

Abstract

End-of-life communication between patients, their family members, and healthcare providers is essential to quality care at the end-of-life. Advance care planning is increasingly utilized to facilitate end-of-life communication, but heart failure patients in particular face numerous challenges to achieving adequate end-of-life communication. Extant literature has highlighted the inherent uncertainty in heart failure as a barrier to end-of-life communication as well as the role of time perspective on the experience of heart failure patients, but little empirical research has been conducted to examine the impact of these constructs. The sample included 168 participants with heart failure who were recruited online through ResearchMatch and the American Heart Association support forum. Correlational data did not support a relationship between uncertainty in illness and end-of-life communication, but revealed significant associations between end-of-life communication and two dimensions of time perspective (i.e., past-negative, present-hedonistic). In contrast, hierarchical regression analysis revealed that uncertainty in illness predicted unique variance in end-of-life communication, and two dimensions of time perspective (i.e., past-positive, future) moderated this relationship. At high levels of uncertainty in illness, past-positive and future orientations were associated with increased end-of-life communication, but at low levels of uncertainty in illness, past-positive and future orientations were associated with decreased end-of-life communication. Study limitations and clinical implications are discussed.

Keywords: heart failure, end-of-life communication, advance care planning

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Uncertainty in the Context of End-of-life Communication in Heart Failure

Advancing technologies and treatment options in cardiac care have enabled people to live longer than ever before. While these developments are a testament to human ingenuity, they have increasingly complicated planning for and making decisions about end-of-life care. These decisions are deeply personal, and the values and beliefs that undergird such decisions vary. Given this diversity, honoring the rights and dignity of patients to choose the course of their medical care is a foundational principle of medical ethics (Riddick, 2003); yet, end-of-life care in concordance with this principle is sometimes lacking. While most people prefer to die at home (Higginson & Sen-Gupta, 2000; Stajduhar et al., 2008; Townsend et al., 1990), the majority of patients now die in a hospital setting, and of those patients, 20% die in intensive care (Cook et al., 2003; Gruneir et al., 2007; Heyland et al., 2000). Many of the patients in intensive care undergo some form of invasive life-sustaining treatment discordant with their wishes (Connors et al., 1995; Krumholz et al., 1998). Furthermore, aggressive medical care at the end of life is contrary to the expressed wishes of most patients (Heyland et al., 2013; Lloyd et al., 2004; Somogyi-Zalud et al., 2002), and substantially impacts their quality of life (Wright et al., 2008, 2010). High quality end-of-life communication between patients and healthcare professionals is key to addressing the gap between patient preferences and medical care. Interventions designed to address the issue of end-of-life communication have ballooned in recent decades (Brinkman-Stoppelenburg et al., 2014), but end-of-life communication remains inadequate for certain patient populations, in particular for heart failure patients (Barclay et al., 2011). Recent findings suggest as many as 1 in 5 heart failure patients express end-of-life treatment preferences that are discordant with

physician orders (Young, Wordingham, et al., 2017). On the basis of such high discordance rates, understanding the barriers to quality end-of-life communication for heart failure patients has become a growing field of inquiry. Yet, fully appreciating the factors that hinder end-of-life communication for this patient population first requires a rudimentary understanding of heart failure.

Heart Failure

Heart failure results when the heart muscle is unable to pump the amount of blood needed to satisfy the metabolic demands of the body (Lilly, 2016). It can manifest from a number of conditions, including systemic or pulmonary hypertension, myocardial infarction, atherosclerosis, cardiomyopathy, or congenital heart disease (Profant & Dimsdale, 2000). The American Heart Association (AHA) defines heart failure as “a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill or eject blood” (Hunt et al., 2005). Heart failure affects approximately 5.7 million patients in the United States with 670,000 patients diagnosed each year (Roger et al., 2012). As prevalence rates increase, in part due to an aging population, projections estimate that heart failure will affect 8 million people in the US by the year 2030 (Heidenreich et al., 2013). It accounts for approximately 800,000 emergency department admissions annually (Collins et al., 2013), and is the leading cause of hospitalizations in adults over the age of 65 (Roger, 2010). Despite improvements in medical intervention, more than half of heart failure patients are likely to die within five years of receiving a diagnosis (Bueno et al., 2010) and 20-30% die after one year (Levy et al., 2002). Given the prognosis associated with heart failure, it has been described as more “malignant” than most cancers (Stewart et al., 2001). The

scale of this public health issue has led many researchers to declare heart failure an epidemic (McCullough et al., 2002; Roger, 2013). Yet, the alarming morbidity and mortality rates associated with heart failure do not fully encompass the reasons why end-of-life issues are of great concern for this patient population.

Heart failure is a chronic illness characterized by progressive deterioration in physical functioning, punctuated by acute medical crises leading to hospitalization (Lunney et al., 2003). Since heart failure is marked by sudden changes in condition, prognosis or illness trajectory is often unpredictable (Lunney et al., 2003). Approximately 50% of deaths among heart failure patients are sudden, from arrhythmias or ischemic events (Orn & Dickstein, 2002), and many of these patients are reported to have good quality of life in the months prior to their death (Levenson et al., 2000). The risk of sudden death in heart failure patients is five times higher than the general population (Mosterd et al., 2001). Although multiple algorithms have been developed to identify patients at risk for sudden death (Goda et al., 2011; Lee et al., 2003), these models were not derived from advanced heart failure populations and tend to underestimate risk as the illness progresses (Whellan et al., 2014). Hence, advancements in risk stratification have not yet ameliorated the significant challenges to determining individual prognosis. As prognostic conversations often lay the groundwork for discussions regarding the end-of-life, prognostication is a central challenge for end-of-life communication in this patient population. This leads to uncertainty as being fundamental to the lived experience of most heart failure patients (Fry et al., 2016; Hopp et al., 2010; Paturzo et al., 2016; Winters, 1999). It is not surprising that end-of-life communication is often deferred until serious medical situations develop (Golin et al., 2000; Murray et al., 2002), which can

lead to in-the-moment treatment decisions incongruent with patients' wishes. To begin addressing the way in which uncertainty impacts end-of-life care for this patient group, a description of what is meant by end-of-life communication is warranted.

End-of-Life Communication

Conceptually, end-of-life communication is defined as a "clinical interaction that involves discussion of death and dying," followed by documentation of the decisions and plans made during the course of the discussion (Sinuff et al., 2015). The primary goal of end-of-life communication is to generate a shared understanding of the patient's values and treatment preferences, and to empower the patient to make the choices that most accurately reflect his or her values and needs (Roter & Fallowfield, 1998). In keeping with the principles of medical ethics (Riddick, 2003), the guiding theoretical approach to effective end-of-life communication is one that is patient-centered (Laine & Davidoff, 1996). While end-of-life communication is an interactive process in a relational context (i.e., doctor-patient relationship), a patient-centered approach is founded on patient autonomy and informed consent; ultimately, patients are responsible for decisions regarding the course of their own lives. Theorists have described end-of-life communication as consisting of both advance care planning and documentation of decisions made during the course of communication (Sinuff et al., 2015).

Advance care planning is a communicative process that involves patients planning for when they are unable to make autonomous healthcare decisions. Advance care planning requires a discussion of a person's values and preferences for future treatments (Sinuff et al., 2015). Values refer to the person's principles or priorities when it comes to death and dying, while preferences include the health states or specific treatments desired

by the person. Given that patient preferences tend to change over the course of illness trajectory, advance care planning is conceptualized as an iterative process, comprising many conversations over time rather than a one-off event (Sudore & Fried, 2010).

Advance care planning includes discussions regarding many aspects of end-of-life treatment, such as cardiopulmonary resuscitation (CPR), the use or deactivation of implantable cardioverter defibrillators (ICD) or left ventricular assist devices (LVAD), surgical procedures, future hospitalization, and the designation of a “health care proxy,” or “surrogate decision maker.” Often named as such, chosen family and caregivers frequently play an important role in advance care planning (High, 1994). As many as 3 out of every 4 patients are at risk of being unable to participate in their own medical decisions at the end-of-life (Silveira et al., 2010), which highlights the designation of a surrogate decision maker as being imperative. Although the process of making medical decisions for someone else can be highly stressful (Anderson et al., 2008) and many surrogates feel unprepared (Fried & O’Leary, 2008), having at least some understanding of patients’ values and treatment preferences through iterative engagement in end-of-life communication can ease this burden (Vig et al., 2007).

Another component of end-of-life communication is documentation of advance care planning (Sinuff et al., 2015). The most common example of end-of-life communication documentation is the advance directive, a legally binding document that outlines a patient’s preferences for future treatment near the end-of-life (e.g., “living will”). The Patient Self-Determination Act, passed by the U.S. Congress in 1991, requires that information about advance directives be presented to patients upon hospital admission (Tanner, 2015). Despite this requirement, many patients continue to lack

advance directives on file (Butler et al., 2015). Hence, many medical institutions have now begun to use a variety of forms including “Physician Orders for Life-Sustaining Treatments,” “Goals of Care Designations,” and “Medical Orders for the Scope of Treatments” that document medical orders in terms of levels of treatment (e.g. Full Treatment, Limited Treatment, Comfort Care). End-of-life communication documentation can be an essential tool for prompting situation-specific advance care planning discussions in addition to providing the basic informational framework for communicating about future care options and patient preferences.

Given these definitions, end-of-life communication is an essential aspect of improving end-of-life care (Allen et al., 2012). While some suggest the use of advance directives alone is inadequate to meet the needs of patients approaching death (Hickman et al., 2005), data regarding their effectiveness is mixed (Brinkman-Stoppelenburg et al., 2014). In general, advance care planning and end-of-life communication documentation have increased medical care compliance with patients’ wishes at the end-of-life (Detering et al., 2010; Wright et al., 2008), and decreased the use of aggressive medical care (Teno et al., 2007) as well as reduced hospitalization (Molloy et al., 2000). Moreover, a review of the literature regarding more complex advance care planning interventions maintains they are largely effective at improving end-of-life care (Brinkman-Stoppelenburg et al., 2014). As a result, multiple randomized controlled trials of complex advance care planning interventions are currently underway for heart failure patients (Denvir et al., 2016; Sadeghi et al., 2016). Nevertheless, the prevalence and quality of end-of-life communication in this patient population remains inadequate (Young et al., 2017) urging

further examination into the factors relevant to heart failure patients that hinder such discussions.

End-of-Life Communication in Heart Failure

Over the past two decades, a growing body of literature has documented the limited extent to which heart failure patients engage in end-of-life communication (Barclay et al., 2011; Garland et al., 2013). Basic conversations about heart failure illness trajectory and future treatment options appear to be lacking, let alone the more complex process of engaging patients in end-of-life communication. For instance, several studies have documented that the majority of heart failure patients have not discussed general disease progression (Harding et al., 2008; Selman et al., 2007) or their individual prognosis with their doctor (Barnes et al., 2006; Gott et al., 2008; Rodriguez et al., 2008; Strachan et al., 2009). Other research has found that few heart failure patients have discussed cardiopulmonary resuscitation (CPR) or the use of other life-sustaining interventions (Ågård et al., 2000; Formiga et al., 2004; Heffner & Barbieri, 2000). In light of these findings, it is not surprising that few patients recall discussing their preferences regarding end-of-life care with their physicians (Boyd et al., 2004; Formiga et al., 2004; Gott et al., 2008; Harding et al., 2008; Klindtworth et al., 2015; Murray et al., 2002; Selman et al., 2007). In fact, several studies conducting interviews with heart failure patients have found that a strikingly small number of patients (e.g., only 2 of 80 patients; Formiga et al., 2004) have reported engaging in any aspect of end-of-life communication (Ågård et al., 2000; Gott et al., 2008; Harding et al., 2008).

While it is clear that many heart failure patients report end-of-life communication is lacking, the exact extent of end-of-life communication in this patient population can be

difficult to determine. The majority of these studies are qualitative in nature, and they examine only limited aspects of end-of-life communication. For instance, Ågård et al. (2000) focused exclusively on patients' understanding and communication with respect to CPR. The research in this area also primarily relies on retrospective reports gleaned from open-ended interview formats; hence, these findings may be prone to biases in patients' memory or understanding of their past communication with their healthcare providers. Only two studies have tried to address this issue using a prospective design by conducting multiple qualitative interviews over the course of a year (Boyd et al., 2004; Murray et al., 2002). Few patients had discussed their end-of-life treatment preferences with their physicians despite many experiencing "brushes with death" (Boyd et al., 2004), and even in the face of worsening symptoms, patients rarely discussed prognosis with their doctors and did not feel involved in their treatment decisions (Murray et al., 2002). These studies provide further evidence that rudimentary end-of-life communication is lacking for heart failure patients even when followed longitudinally. Yet, like many of the qualitative studies conducted in this area, they do not provide quantitative information regarding specific aspects of end-of-life communication.

One of the few investigations to quantify the extent of end-of-life communication in this patient population found that only 11% of patients had discussed prognosis with their doctor and only 26% had spoken to their doctor about their preferences regarding life-sustaining treatments (Strachan et al., 2009). These empirical findings corroborate earlier qualitative data suggesting the end-of-life communication needs of heart failure patients are not being met. Interestingly, some researchers have reported that as many as 75% of heart failure patients show "some evidence" of having engaged in end-of-life

communication, based on a review of their medical chart or the recall of a nurse following their death (Johnson et al., 2009); yet, the authors do not say what qualified as evidence of end-of-life communication or how those judgments were made. More recent research reviewing the medical records of 3,592 patients has more specifically demonstrated that only 12% of heart failure patients had a documented advance directive in their medical chart (Butler et al., 2015). Thus, despite limited evidence that end-of-life communication may occur at a higher rate than what heart failure patients report, the preponderance of evidence indicates that heart failure patients rarely engage in end-of-life communication with their physicians.

Nevertheless, some patients prefer to not think about their prognosis (Ågård et al., 2004; Barnes et al., 2006) and deliberately eschew obtaining prognostic information from their physician (Gott et al., 2008). Some patients have an inchoate awareness of their unfavorable prognosis, but prefer to not discuss it openly (Horne & Payne, 2004; Rogers et al., 2000; Strachan et al., 2009), while other patients avoid discussing death and dying altogether (Ågård et al., 2004; Boyd et al., 2004; Heffner & Barbieri, 2000; Rogers et al., 2000). In some cases, patients' consider end-of-life issues as not being pertinent to their situation (Strachan et al., 2009), or may not be confident in their ability to make informed end-of-life treatment choices and choose to relinquish control of their healthcare decisions to their treatment providers (Ågård et al., 2004). Although the underlying motivations are sometimes unclear, these findings highlight that a portion of heart failure patients tend to avoid end-of-life communication while some see it as a matter of little concern to them. However, a substantial portion of heart failure patients report that end-of-life communication would be of great benefit to them (Aldred et al., 2005; Bekelman

et al., 2011; Caldwell et al., 2007; Harding et al., 2008; Heffner & Barbieri, 2000; Rodriguez et al., 2008; Strachan et al., 2009), which highlights the importance of considering individual differences in any approach to enhancing end-of-life communication. Moreover, an improved understanding of the underlying factors that impede engagement in these discussions is an important step towards meeting this patient need.

Uncertainty and End-of-Life Communication

Reviews focused on end-of-life communication in heart failure have consistently implicated uncertainty as being a major barrier to patients' engagement in the advance care planning process (Ahluwalia & Enguidanos, 2015; Barclay et al., 2011; Garland et al., 2013). The unpredictable trajectory of heart failure (Lunney et al., 2003) along with the high risk of sudden death (Mosterd et al., 2001; Orn & Dickstein, 2002) creates an unavoidable degree of uncertainty with respect to patients' prognoses. This inherent uncertainty is further exacerbated by the complexity of medical regimens recommended for effective symptom management (Azad & Lemay, 2014) as well as the inevitability of patients having to make tough choices that involve complicated trade-offs regarding their medical care (Allen et al., 2012). In addition, the majority of the heart failure population are elderly patients (Heidenreich et al., 2013) with high rates of co-morbid medical conditions (Braunstein et al., 2003). This substantially convolutes the process of distinguishing between symptoms indicative of decline in cardiac function from those related to another illness or typical of aging. Hence, ambiguity with respect to recognizing and evaluating the severity of symptoms and confusion around their management adds to the already existing lack of clarity in prognosis. Compounded by the

difficulty in predicting the sudden, intermittent medical crises characteristic of the condition (Lunney et al., 2003), uncertainty develops into a pervasive part of living with heart failure and subsequently limits the extent to which patients' think about and plan for their future (Hopp et al., 2010; Paturzo et al., 2016).

However, the reviews describing uncertainty's central role in the inadequacy of end-of-life communication for heart failure patients are based almost entirely on qualitative interviews of patients and their healthcare providers with no allusion to theory as a way to frame and thereby fully understand this relationship (Ahluwalia & Enguidanos, 2015; Barclay et al., 2011). In addition, the failure of many early advance care planning interventions (e.g., Connors et al., 1995) has been attributed to their lack of a theoretical basis, which remains largely unaddressed due to the willingness of health funding agencies to support projects without a strong theoretical foundation (Hines, 2001). Even current complex advance care planning interventions designed specifically for heart failure patients (Denvir et al., 2016; Sadeghi et al., 2016) are only loosely based on a model of shared decision-making (Elwyn et al., 2012). Moreover, shared decision-making models do not provide a full account of the psychosocial and emotional factors known to impact end-of-life communication, which produces interventions that are noncomprehensive and offer a blanket approach to addressing inadequacies in end-of-life communication rather than an ideally nuanced and individualized process for each patient. Although interventions designed to enhance end-of-life communication for heart failure patients might benefit from a theoretically driven empirical approach to addressing uncertainty, very little research has been conducted to elucidate the

relationship between heart failure patients' experience of uncertainty and end-of-life communication in the context of a theoretical framework.

Uncertainty in Illness

Building on the cognitive appraisal framework outlined by Lazarus and Folkman (1984) and early conceptual work on the nature of uncertainty (Budner, 1962), Mishel developed a model to understand uncertainty when applied to health and illness contexts (Mishel, 1988a). Mishel (1988b) defines uncertainty as a neutral cognitive state that arises from the inability to construe meaning from illness-related events. Individuals unable to recognize or appropriately classify such events are theorized to lack an existing cognitive schema (i.e., internal representation of the situation or event; Mishel, 1981) through which to interpret available cues, thus producing the experience of illness uncertainty (Mishel, 1988a). Psychometric findings highlight two primary dimensions of the uncertainty experience: multiattributed ambiguity and unpredictability (Mishel, 1981). Multiattributed ambiguity denotes a general lack of clarity across illness-related events (e.g., diagnosis, symptom management, and prognosis), whereas unpredictability refers to the inability to forecast symptomology and illness outcome (Mishel, 1981). Two additional factors related to the complexity and lack of available diagnostic and treatment information pertinent to the condition were also proposed (Mishel, 1981).

Organization of the model delineates three components or "themes": 1) antecedents of uncertainty, 2) appraisal of uncertainty, and 3) coping with uncertainty (Mishel, 1988a). According to Mishel (1988b), antecedents include contextual factors pertaining to the individual (e.g., cognitive capacity) and their situation (e.g., social support) as well as illness-specific characteristics (e.g., symptom pattern) that bear on the

perception of illness-related events. Even though these antecedent variables shape the perception of uncertainty, the state of uncertainty is posited to be neutral until it is appraised; that is, until it is evaluated as threatening/negative or perceived as an opportunity/positive (Lazarus, 1974; Mishel, 1988a). In addition, the way in which uncertainty is appraised subsequently influences the process by which individuals manage or cope with the experience (Mishel, 1988a). Descriptions of relevant coping strategies have varied within the literature (Lazarus & Folkman, 1984; Miller, 1996; Mishel, 1988a), but the strategies most appropriate to illness uncertainty include “mobilizing” strategies, such as information-seeking, as well as avoidance strategies and cognitive reappraisal strategies (Afifi & Weiner, 2004; Mishel, 1990).

In Mishel’s (1988) original model, uncertainty is generally assumed to be aversive and often appraised as threatening, leading to adaptive coping strategies primarily aimed at reducing or eliminating uncertainty. Uncertainty is only appraised as positive in extreme situations when framing uncertainty as an opportunity may be advantageous, such as when receiving a definitive terminal prognosis. Although evidence provided early support for this framework (Mishel & Braden, 1988; Yarcheski, 1988), research that included patients diagnosed with long-term chronic illnesses demonstrated that uncertainty was sometimes appraised as being positive even in situations when patients had not received a definite terminal prognosis (Hilton, 1988; King & Mishel, 1986; Mishel, 1988b; Mishel & Murdaugh, 1987). This prompted Mishel’s (1990) reconceptualization of the uncertainty in illness model to include the experience of those with long-term, chronic conditions. Mishel’s (1990) expanded view of uncertainty acknowledges that reducing or eliminating uncertainty for some chronically ill patients is

an untenable goal. Rather, long-term adaption entails reframing uncertainty as an acceptable part of life and integrating a more probabilistic style of thinking and world view (Mishel, 1990; Selder, 1989). Whereas uncertainty is still likely to be viewed as threatening in the early-stages of an illness or during abrupt changes, such as an acute medical crisis (Becker et al., 1993; Mishel & Murdaugh, 1987), the negative impact of uncertainty diminishes after years of living with a chronic condition (Flemme et al., 2005; Mauro, 2010). The theory also highlights six factors presumed to underlie uncertainty in chronic illness: the nature of the illness, the future being unknown, changes in one's self-concept, lack of information, degree of social support, and the influence of health care providers (Mishel, 1999).

There is an extensive research literature demonstrating empirical support for the Uncertainty in Illness model across health contexts (Mast, 1995; Mishel, 1997, 1999; Stewart & Mishel, 2000). The model has been applied fruitfully to a wide variety of health conditions, including cancer (Cahill et al., 2012; Hilton, 1988), AIDS (Weitz, 1989), multiple sclerosis (Wineman, 1990), hepatitis C (Reinoso & Türegün, 2016), fibromyalgia (Johnson et al., 2006), and other chronic pain samples (Wright et al., 2009). The negative impact of uncertainty on patient outcomes has also been well documented in the uncertainty in illness literature. Experimental studies have shown that uncertainty distorts the interpretation and evaluation of situations/events and undermines adaptive future planning (Grupe & Nitschke, 2013). Additionally, experimental evidence points to uncertainty as amplifying an individual's awareness of and sensitivity to illness-related events (Rhudy & Meagher, 2000; Sawamoto et al., 2000). Such findings provide insight into the robust association between uncertainty and poor psychological outcomes, such as

anxiety (Kuang & Wilson, 2017; Warrington & Gottlieb, 1987; Wong & Bramwell, 1992), depression (Hawthorne & Hixon, 1994; Wineman, 1990), and poor quality of life (McCain & Cella, 1995; Padilla et al., 1992). Yet, findings among some patients with chronic illness suggest the relationship between psychological outcomes and uncertainty is not so apparent (Hilton, 1988; Small & Graydon, 1993), which is consistent with Mishel's (1990) supposition that reappraisal and acceptance of uncertainty promotes better long-term adjustment in some patients with chronic illness.

Uncertainty in Illness in Heart Failure Patients

Although uncertainty in illness has been examined across a wide range of medical conditions, quantitative research focused on illness uncertainty in heart failure patients is quite limited. Nevertheless, uncertainty in illness has been shown to have negative impact on patients following a myocardial infarction (Webster & Christman, 1988) or after a life-threatening ventricular arrhythmia (Carroll et al., 1999; Dougherty & Shaver, 1995). Uncertainty in illness has also been reported in patients following either coronary bypass surgery (Redeker, 1992) or coronary angioplasty (White & Frasure-Smith, 1995), and it has been shown to be high among cardiac patients hospitalized on an Intensive Coronary Care Unit (Andersson-Segesten, 1991). Additionally, the uncertainty in illness model has been used to develop a framework for understanding the chronic uncertainty experienced by cardiac patients with an Implantable cardioverter-defibrillator (ICD; Carroll et al., 2014). Carroll and colleagues (2014) constructed their adaptation model based on findings from two longitudinal studies measuring illness uncertainty in patients over the course of seven years (Flemme et al., 2005) and nine years (Mauro, 2008, 2010) after their ICD implantation. Both studies reported a high degree of uncertainty in the patients'

first year post-ICD implant, and uncertainty being associated with poor psychosocial adjustment. However, Flemme et al. (2005) found a decline in the reported degree of uncertainty over the long-term, whereas Mauro (2010) continued to observe moderate levels of uncertainty throughout the investigation, despite both noticing significant improvements in psychosocial adjustment over time. That is, most patients with an ICD appear to adjust adequately to their situation provided enough time, but a consistent picture as to the extent patients continue to feel uncertain over time remains unclear. This research has demonstrated the utility of using uncertainty in illness as a framework for investigating psychosocial phenomena specific to cardiac populations.

Few studies have examined heart failure patients framed within the uncertainty in illness perspective. Although the psychosocial heart failure literature provides substantial qualitative support for the notion that “uncertainty” illy-defined is fundamental to the experience of most heart failure patients; to date, only four published studies have quantitatively examined the uncertainty construct using measures derived from Mishel’s Uncertainty in Illness Scale (MUIS; Mishel, 1981). Winters (1999) found that most heart failure patients report a moderate degree of illness uncertainty consistent with most patients with chronic illness (Mishel, 1999). Patients who were diagnosed more recently or waiting to receive test results reported higher levels of uncertainty, though uncertainty was reported even by those with a long-term diagnosis and stable symptom presentation (Winters, 1999). Lending support to Mishel’s theory of uncertainty in chronic illness (1990), heart failure patients’ uncertainty was increased when they experienced changes in their symptoms or treatment regimen, when they had difficulty distinguishing illness-related symptoms from those of normal aging, when information was perceived as

incomplete or too complex to understand, and when dwelling on their condition and the future as being unknown (Winters, 1999). Heart failure patients with greater uncertainty in illness have been shown to exhibit more depressive mood symptoms and report reduced quality of life (Hawthorne & Hixon, 1994), but some heart failure patients suggested that the uncertainty regarding the circumstances of their death has afforded them an opportunity to hope for longevity and maintain their “wait and see” approach to seeking healthcare services (Winters, 1999). These preliminary data support the applicability of Mishel’s model of uncertainty in chronic illness to heart failure patients, but both studies are limited by small sample sizes ($N = 24$; $N = 22$; respectively). Additional findings from a cross-section of 93 heart failure patients regarding fatigue provides further evidence that symptom severity and concomitant physical functioning impact patients’ perceptions about the uncertainty of their future (Falk et al., 2007). Nevertheless, recent findings suggest interventions that emphasize a person-centered approach to relieve symptom burden and improve quality of life have proved successful in reducing heart failure patients’ self-reported uncertainty in illness (Dudas et al., 2013). Such findings may hold promise to enhance heart failure patients’ self-confidence and ability to manage their illness, but rigorous examination of relationship between uncertainty in illness and end-of-life communication is needed.

Factors Relevant to Uncertainty in Illness and End-of-Life Communication

Identifying variables relevant to the relationship between uncertainty and limited engagement in end-of-life communication may provide an avenue for bolstering heart failure patients’ desire for engagement, ultimately facilitating quality end-of-life care. Despite a dearth of direct empirical evidence elucidating such variables, there has been a

great deal of qualitative research highlighting several barriers to these discussions that take on new meaning when framed from an uncertainty in illness perspective. For instance, lack of available information and knowledge pertaining to heart failure is a major concern for this patient population (Ahluwalia & Enguidanos, 2015; Barclay et al., 2011). In addition, emotional and dispositional factors shape patients' level of engagement with medical decisions and end-of-life communication (Barclay et al., 2011; Garland et al., 2013). A recent qualitative analysis mapping trajectories of the uncertainty experience in advanced illness also highlighted patients' temporal focus and perceptions regarding the future as highly relevant (Etkind et al., 2017). Research focused on temporal perspectives is an important aspect of patients' motivation to engage in health behaviors, yet almost no research has examined temporal focus in the context of end-of-life communication.

Temporal Perspectives and Health Behaviors

Time perspective broadly encompasses the attitudes, cognitions, and emotional valence associated with an individual's personal history, present experience, and imagined future (Carney & Patrick, 2017). It has long been argued that the personal views regarding one's past, present, and future provide a context that imbues our experiences with order and meaning (Lewin, 1951). Moreover, past events as well as those anticipated in the future have been proposed to exert influence on present behavior through their manifestation as cognitive representations (Nuttin & Lens, 1985), a notion central to modern social-cognitive theory (Bandura, 1997) in that behavior is based on beliefs rooted in previous experiences, present appraisals, and anticipated future consequences. Building on such work, contemporary theorists advance time perspective

as a cognitive process fundamental to human psychological functioning (Zimbardo & Boyd, 1999) and a critical aspect of human motivation (Carstensen et al., 1999).

Researchers have suggested that time perspective may have particular relevance to the field of health psychology (Lennings, 2000; Zaleski, 1994), and a small but growing literature has documented the influence of time perspective on various health behaviors (Gellert et al., 2012; Henson et al., 2006; Stahl & Patrick, 2012). For instance, differences in time perspective have been found to be predictive of individuals' success meeting goals related to physical activity (Gellert et al., 2012) and long-term smoking cessation (Adams, 2009; Hall et al., 2014), in addition to being useful as a predictor for specific health-promoting behaviors such as screening for breast cancer (Griva et al., 2013) and cervical cancer (Roncancio et al., 2014). There is also evidence that time perspective may play an important role in the health-related attitudes and behaviors of individuals participating in cardiac rehabilitation (Hamilton et al., 2003). However, much less is known about the influence of time perspective on motivation and behavior related to end-of-life concerns in cardiac populations.

Recent research has pointed to patients' temporal focus as a major theme of uncertainty for those suffering from life-limiting illness (Etkind et al., 2017). Etkind and colleagues (2017) noted that some patients tend to live squarely in the present while others focus on their potentially shortened future, and this shapes how patients experience and respond to uncertainty. Heart failure patients stood out in particular due to their shifting temporal focus related to unpredictable illness-events (Etkind et al., 2017). While some heart failure patients recognize the imminence of death (Klindtworth et al., 2015; Strömberg & Jaarsma, 2008), not acknowledging this inevitability and living in the

present appears to be an important coping mechanism for others (Gott et al., 2008).

During stable periods of their disease trajectory, heart failure patients may focus more on the present and meeting the demands of their ongoing complex treatment regimens (Aldred et al., 2005; Gott et al., 2008; Jani et al., 2013; Klindtworth et al., 2015); that is, until an acute exacerbation of their illness compels them to consider death and their end-of-life care (Willems et al., 2004). Some findings suggest age may be a factor as younger heart failure patients tend to focus on maintaining hope and controlling their symptoms while older patients are more likely to acknowledge their impending death (Selman et al., 2007). In general, the unpredictability of heart failure leaves many patients feeling uncertain about their future, which is best summed up by one heart failure patient's statement, "I try to live my life without thinking about my future, but sometimes there grows up inside of me a deep sense of uncertainty" (pg. 268; Paturzo et al., 2016).

A recent meta-analysis examining uncertainty's effect on motivational coping strategies in illness contexts suggests age is a significant moderator of this relationship (Kuang & Wilson, 2017). Older adults were less likely to seek important health information than younger adults when faced with uncertainty (Kuang & Wilson, 2017). These findings were interpreted as consistent with socioemotional selectivity theory, a life-span theory of motivation and goal-directed behavior. Socioemotional selectivity theory posits the subjective sense of time remaining until death, or future time horizon, plays a key role in motivational tendencies (Carstensen et al., 1999). Changes in time horizons are theorized to influence the types of goals one is motivated to pursue. In general, those with open-ended or expansive time horizons tend to prioritize gathering information, as they are oriented towards expanding their knowledge, while those with

limited time horizons prioritize current emotional states in order to enhance psychological well-being. Given that older adults theoretically have more constrained time horizons, socioemotional selectivity theory was originally developed to account for motivational shifts found to occur as part of the aging process (Carstensen, 2006). For instance, older adults are more likely to limit their social networks and pursue goals that deepen current interpersonal relationships (Wrzus et al., 2013).

Older adults also exhibit a cognitive bias for positive rather than negative material, known as the “age-related positivity effect” (Mather & Carstensen, 2003, 2005). Older adults are more likely to attend to and remember positive stimuli compared to younger individuals (Charles et al., 2003; Mather & Carstensen, 2003; Mikels et al., 2005). According to socioemotional selectivity theory, the age-related positivity effect reflects a top-down shift in goal-directed cognitive processing in response to changing time horizons (Reed & Carstensen, 2012), a finding that is reliable and robust (Reed et al., 2014) and largely a function of time horizons rather than age (Löckenhoff & Carstensen, 2007). Thus, it is perceived time horizons that play an important role in the types of goals that are prioritized and the way in which information relevant to those goals is processed. The posited role for perceived time horizons in goal-directed behavior may be especially relevant to heart failure patients because the condition both shortens one’s future and largely affects the elderly (Roger, 2013). Moreover, the impact of perceived time horizons may be particularly manifest in end-of-life communication, as these conversations involve processing difficult medical information and voicing goals for future care.

End-of-life discussions can be emotion-laden. Research suggests that individuals with limited time horizons demonstrate increased emotion regulation capacities during emotionally charged situations (Carstensen et al., 2000) and tend to prioritize emotionally meaningful goals (Sullivan-Singh et al., 2015). However, it is possible that individuals with limited time horizons may tend to disregard important negative information, even when making healthcare decisions, as a strategy to manage their affect by avoiding potentially upsetting information (i.e., positivity effect; Löckenhoff & Carstensen, 2007, 2008; Mather et al., 2005). Recent work suggests that when health status is poor, individuals purposefully attend to more negative health information, even when time horizons are limited (i.e., negating the positivity effect); however, when health status is good, the positivity effect continues to operate (English & Carstensen, 2015). Since many heart failure patients are elderly (Roger, 2013) who tend to report good quality of life even in the six months prior to their death (Levenson et al., 2000), the positivity effect may underlie the tendency for some patients to avoid end-of-life communication as an emotional coping strategy (Gott et al., 2008); that is, until an acute medical crisis makes apparent the need to discuss and plan their future medical care.

Despite the substantial literature on time horizons and older adults, little research has investigated the effect of time horizons on end-of-life communication directly. Luth (2016) examined the influence of time horizons on the completion of advance directives in 305 adults many of whom (206) had a diagnosis of heart failure, cancer, or diabetes. Individuals with a “limited” time horizon (i.e., perceived life expectancy of less than 5 years), were less likely than those with an “intermediate” time horizon (i.e., perceived life expectancy of more than 5 but less than 10 years) to have completed an advance directive

or appointed a durable power of attorney. Those with an “expansive” time horizon (i.e., perceived life expectancy of more than 10 years) were less likely than either to have end-of-life communication documentation. When examined in conjunction with the findings reported by Kuang and Wilson (2017), it would appear that patients who are experiencing a high degree of uncertainty, in general, are more likely to use avoidance as their primary coping mechanism rather than more “active” strategies (Kuang & Wilson, 2017). Additionally, this tendency may be exacerbated in individuals with a limited time horizon given their predisposition to prioritize in-the-moment emotional needs by avoiding negatively evocative information. These implications are concerning in light of the fact that patients with more limited time horizons may actually prefer fewer life-sustaining interventions when presented with hypothetical illness scenarios (Allen et al., 2011). Hence, it may be important to consider the intersection of time perspective and uncertainty in illness in order to better understand patients’ willingness to engage in difficult end-of-life conversations with their physician and loved ones.

A significant limitation of the extant literature regarding time perspective and end-of-life concerns is an overreliance on a single future-oriented dimension of time perspective, as posited in socioemotional selectivity theory. Within the broader health psychology literature, time perspective is generally regarded as a multidimensional construct that also includes cognitive frames related to the past as well as the present (Carney & Patrick, 2017). Likewise, the tendency to focus on future time perspective at the exclusion of other important dimensions has been a critique levied at the majority of time perspective research (Boniwell & Zimbardo, 2012). There is empirical evidence that a comprehensive conception of time perspective includes five distinct dimensions that

bear on our motivations and behavior (i.e., future, past-positive, past-negative, present-hedonistic, and present-fatalistic; Zimbardo & Boyd, 1999). According to Zimbardo's model of time perspective, these orientations are not mutually exclusive and may vary within an individual across life situations. For instance, someone may be future-oriented when planning their career but exhibit a present-hedonistic orientation when socializing with friends. Yet, individual differences in general disposition toward certain orientations compared to others is demonstrated to be a relatively stable metric with substantial predictive utility (Carney & Patrick, 2017; Zimbardo & Boyd, 1999). Although research using a multidimensional framework for time perspective in cardiac populations is limited, Hamilton and colleagues (2003) present evidence that the past and present dimensions of time perspective may in fact be more predictive of important health behaviors than future time perspective in individuals in cardiac rehabilitation. Moreover, individuals with a "limited" time perspective may be more accurately conceptualized as having shifted to a predominantly present- or past-oriented time perspective. This illustrates the utility of using a multidimensional model of time perspective, particularly in populations that have experienced a significant health crisis due to the potential for significant shifts in time orientation, although research in this area is quite limited. By the same principle, understanding the interaction between uncertainty in illness and the various dimensions of time perspective may provide greater insight into the underlying psychological phenomena that influence patient engagement in end-of-life communication.

Background Summary

Quality end-of-life care entails communication between patients, surrogate decision-makers, and healthcare providers about future expectations and preferences for medical care (Sinuff et al., 2015). Iterative conversations and frequently updated documentation help to ensure treatment at the end-of-life is carried out in concordance with each patient's values and goals for future care (Sudore & Fried, 2010). Despite the rapid rise of advance care planning initiatives to facilitate end-of-life communication (Brinkman-Stoppelenburg et al., 2014), reviews of this burgeoning literature suggest the results while encouraging may be overstated. Lund and colleagues (2015) point out that many of the trials evaluating implementation of complex advance care planning interventions focus heavily on improving administrative procedures and organizational mechanisms (e.g., patient selection criteria, standardization of decision tools) in order to improve end-of-life communication rather than examining the actual quality of communication. In addition, many advance care planning interventions reporting successful outcomes have based their findings on simplified approximations of quality end-of-life care, such as reduced healthcare-care costs and an increase in the number of home deaths (Brinkman-Stoppelenburg et al., 2014; Pollock & Wilson, 2015). Notwithstanding, there is consensus that enhancing the communication between patient and provider is fundamental to effective advance care planning; hence, many interventions have been developed that employ independent teams of healthcare professionals with specialized skills-training to guide end-of-life communication (Lund et al., 2015), which may prove impractical for healthcare systems that lack the financial resources and infrastructure required to integrate such interventions into routine clinical

care. Solutions such as highly structured and simplified conversation guides and decision-making support tools offer the promise of greater standardization and efficiency of services that can be provided without the need for specialized communication skills training. However, conversations about death and dying are emotionally demanding, complex, and highly variable, leaving providers and patients with the challenging task of initiating and navigating these conversations regardless of how advanced or easy to use clinical tools designed to support these conversations become.

Current Study Rationale

Although research findings generally point to the benefits of end-of-life communication as well as considerable desire among patients and caregivers for open and honest discussions regarding their care (Detering et al., 2010; Teno et al., 2007), a substantial number of patients are not receptive to end-of-life communication, even when death is imminent (Barclay et al., 2011; Momen & Barclay, 2011). This is particularly problematic for the healthcare providers who are responsible for discerning which patients are receptive to end-of-life communication and those who are resistant to engaging in such discussions. Circumspection on the part of both patients and providers may be intended to preserve hope and respect patient autonomy (Barclay et al., 2011), but decades of research in end-of-life care challenge these assumptions and highlight the call from patients, caregivers, and providers for an improved provision of end-of-life care. Even though this extensive qualitative literature has offered insight as to why some patients remain hesitant to discuss their end-of-life care, the lack of empirical research built on a theoretical foundation limits our understanding of the psychological variables that hinder heart failure patients' engagement in end-of-life communication. A greater

understanding of the psychological variables that undermine end-of-life communication engagement provides novel avenues for increasing the frequency and enhancing the quality of these discussions without eroding the value of patient autonomy. Numerous studies have highlighted the inherent uncertainty many heart failure patients face as a barrier to end-of-life communication (Ahluwalia & Enguidanos, 2015; Barclay et al., 2011; Garland et al., 2013), and Mishel's (1990) model of uncertainty in chronic illness provides a theoretical framework to better understand the impact of uncertainty on end-of-life communication and the pertinent factors that help to elucidate this relationship.

There is also accumulating evidence that time perspective may play an important role in heart failure patients' engagement in end-of-life communication. Qualitative research points to time perspective being a relevant factor in the uncertainty experienced by heart failure patients (Etkind et al., 2017), and the empirical relationship between time perspective and health-promoting behavior is well documented (Carney & Patrick, 2017). Exploring the relationships between uncertainty in illness and a multidimensional conceptualization of time perspective may provide novel insight into the complex psychological mechanisms that influence end-of-life communication engagement.

Study Aims and Hypotheses

Aim 1: Apply Mishel's (1990) model of uncertainty in chronic illness to heart failure patients as a framework for clarifying the role uncertainty plays in end-of-life communication. Elucidate the relationship between uncertainty in illness and participants' engagement in end-of-life communication.

HI: It was hypothesized that uncertainty in illness is negatively correlated with end-of-life communication (ACPES–Action Score).

Aim 2: Determine whether time perspectives play a role in heart failure patients' engagement in end-of-life communication. Identify and examine the influence of multiple dimensions of time perspective (i.e., present-hedonistic; present-fatalistic; past-negative; past-positive; future) on engagement in end-of-life communication.

H2: It was hypothesized that a present-hedonistic temporal orientation is negatively correlated with end-of-life communication.

H3: It was hypothesized that a present-fatalistic temporal orientation is negatively correlated with end-of-life communication.

H4: It was hypothesized that a past-negative temporal orientation is negatively correlated with end-of-life communication.

H5: It was hypothesized that a past-positive temporal orientation is positively correlated with end-of-life communication.

H6: It was hypothesized that a future temporal orientation is positively correlated with end-of-life communication.

Aim 3: Elucidate the complex relationships between time perspective and uncertainty in illness and their association with end-of-life communication. Examine whether multiple dimensions of time perspective moderate the relationship between uncertainty in illness and end-of-life communication.

H7: It was hypothesized that a significant two-way interaction exists between uncertainty in illness and a present-hedonistic temporal orientation that is associated with end-of-life communication. More specifically, the relationship between uncertainty in illness and end-of-life communication is stronger at higher levels of present-hedonistic time perspective.

H8: It was hypothesized that a significant two-way interaction exists between uncertainty in illness and a present-fatalistic temporal orientation that is associated with end-of-life communication. More specifically, the relationship between uncertainty in illness and end-of-life communication is stronger at higher levels of present-fatalistic time perspective.

H9: It was hypothesized that a significant two-way interaction exists between uncertainty in illness and a past-negative temporal orientation that is associated with end-of-life communication. More specifically, the relationship between uncertainty in illness and end-of-life communication is stronger at higher levels of past-negative time perspective.

H10: It was hypothesized that a significant two-way interaction exists between uncertainty in illness and a past-positive temporal orientation that is associated with end-of-life communication. More specifically, the relationship between uncertainty in illness and end-of-life communication is weaker at higher levels of past-positive time perspective.

H11: It was hypothesized that a significant two-way interaction exists between uncertainty in illness and a future temporal orientation that is associated with end-of-life communication. More specifically, the relationship between uncertainty in illness and end-of-life communication is weaker at higher levels of future-oriented time perspective.

Methods

Participants

Participants were heart failure patients currently receiving treatment from a primary care provider or cardiologist. Inclusion criteria were 18 years of age or older, English language proficiency, a diagnosis of heart failure, and currently receiving treatment from a primary care provider or cardiologist. Exclusion criteria were active psychosis or severe neurological impairment precluding ability to complete the study as determined by the principal investigator. Participants were recruited using two web-based methods, and although the recruitment procedure varied slightly across these methods, inclusion and exclusion criteria remained consistent. The following web-based methods were chosen in order to recruit a large national sample of heart failure patients as opposed to a sample that is limited geographically or by regional healthcare system so as to increase generalizability.

The primary recruitment method employed the use of ResearchMatch, a web-based recruitment registry designed to match individuals wishing to participate in clinical research studies with researchers actively searching for volunteers throughout the United States (Harris et al., 2012). ResearchMatch volunteers were individuals interested in being considered for participation in research studies or trials across the United States who provided medical information including health conditions and current medications. Participants were also recruited through a web-based support group hosted by the American Heart Association's web-based platform.

Procedure

Volunteers in the ResearchMatch registry indicated current medical diagnoses by typing in a description of their conditions (e.g., left-ventricular failure, cardiac failure, congestive heart failure). An algorithm matching their text input to diseases and conditions described in the Unified Medical Language System (UMLS) metathesaurus was used to identify volunteers who met eligibility criteria. All registered volunteers agreed to be contacted about participating in research studies that may recruit based on their medical information provided.

Eligible volunteers were contacted via e-mail that contained IRB-approved language inviting them to participate in the study. This e-mail notification informed volunteers that the study examines future treatment planning among heart failure patients and their experiences related to end-of-life care. Volunteers were asked to indicate whether or not they were interested in participating in the research study or if they would like more information regarding the study prior to participating. Volunteers who indicated that they would like more information were contacted via email, phone, or surface mail depending on the preference indicated. Per the volunteer's preference, a web-based link providing access to the online survey via e-mail or a paper version via surface mail was sent to all volunteers whom indicated an interest in participating in the study.

Participants recruited through the American Heart Association's web-based support group were invited via an advertisement posted on the heart failure forum. Visitors who viewed the posted advertisement were presented with the same IRB-approved language and description of the study noted above. The post also contained

eligibility criteria and contact information for the principal investigator. Participants who preferred to complete the web-based version of the survey were able to access the survey via the web-based link provided in the posted advertisement. Participants who preferred to complete a paper and pencil version of the survey were sent via surface mail a survey packet that included the informed consent and study measures along with a pre-stamped return envelope. Upon completion of the survey, participants could indicate whether or not they would like a brief phone follow-up to answer any questions and provide any necessary emotional support given the nature of the topics broached in the survey. A list of referrals the participant could contact was also provided at the end of the survey in the case that participants did not wish to be contacted for follow-up. Participants did not receive any form of compensation for their involvement in the study.

Materials

Participants completed measures that were collected at one time point. All measures were collected via a web-based computer assisted-survey or a paper and pencil survey packet, depending on the preference of the participant. Access to the web-based version of the survey was provided via a link to the online survey platform managed by Qualtrics. See Appendix A for full versions of the scales described below.

Demographics

Information was collected on the participant's age, gender, sexual orientation, race, religious affiliation, native language, country of origin, marital status, years of education, employment status, occupation, and annual household income.

Medical Status

Participants were asked to report information regarding the diagnoses provided to them by their health care provider as well as other relevant medical information.

Participants indicated how long they have had been diagnosed with heart failure, the type of professional who informed them of their diagnosis, their New York Heart Association (NYHA) Functional heart failure classification, most recent ejection fraction measurement, recent history of hospitalizations, and if they were diagnosed with any comorbid medical conditions. Participants were given the option to indicate “I am not sure” for any questions that they were unable to answer.

Measures

Advance Care Planning Engagement Survey (ACPES). The Advance Care Planning Engagement Survey was originally developed by Sudore and colleagues (2013) and later refined to multiple versions of various lengths (Sudore et al., 2017). The present study uses the Action subscale comprised of 18 dichotomous (yes/no) items that generally examine four domains of end-of-life communication (i.e., designating surrogate decision makers, discussion of treatment preferences, flexibility in decision-making, and communication with medical providers). The number of action items endorsed are summed into a single ordinal variable that represents the extent to which participants have engaged in end-of-life communication. This ACPES-Action Scale was used as the primary outcome of this study.

The Action scale has been used by researchers as a measure of end-of-life communication (Howard et al., 2016; Sudore et al., 2013, 2017), with means scores between 10.1 – 11.2 (SD = 3.6 – 5.6). Although researchers have not calculated internal

consistency for this measure, test-retest reliability calculations show near perfect agreement across administrations (Shrout-Fleiss Intra-class correlation = 0.87; Sudore et al., 2013). As part of this study, the internal consistency reliability of the Action scale was calculated using the Kuder-Richardson-20 coefficient (KR-20), which was developed to measure internal consistency reliability for scales using items with dichotomous answer choices (Cortina, 1993). KR-20 in this study was 0.89.

Uncertainty in Illness (MUIS-Cardiovascular Population Scale). Uncertainty in illness will be measured by the Cardiovascular Population Scale, a disease-specific questionnaire developed by Mishel (1983) based on the original Mishel Uncertainty in Illness Scale (MUIS; (Hallberg & Erlandsson, 1991). The scale consists 16 items measuring uncertainty in illness in cardiac populations. Each item is rated on a 5-point Likert scale, which ranges from 1 (strongly agree) to 5 (strongly disagree). Total scores range from 16 to 80 where higher scores indicate higher degree of uncertainty. The present study uses the total score as opposed to subscales, which examines the ambiguity patients perceive about the severity of their illness, prognosis, and symptomology along with the complexity perceived to surround their illness and its treatment. Items include, “Doctors say things that can be understood in different ways,” and “Since my condition is uncertain and may change, I cannot plan for the future.” The present study uses the Swedish version of the CPS due to its simplified language, which has been shown to be a valid and reliable (Cronbach’s $\alpha = .74$) measure of uncertainty in illness in cardiac populations (Hallberg & Erlandsson, 1991). Cronbach’s alpha in this study was 0.87.

Zimbardo Time Perspective Inventory (ZTPI). Time perspective was assessed using a slightly modified version of Zimbardo and Boyd’s (1999) original 56-item scale

designed to measure an individual's beliefs, attitudes, and disposition regarding temporal experiences across five categories of time perspective. Items are measured on a 5-point Likert scale assessing the extent to which each item is characteristic of their own attitudes. Exploratory and confirmatory factor analysis conducted by Zimbardo and Boyd (1999) has established the following five unique dimensions of time perception: past-negative (i.e., aversive view of the past); past-positive (i.e., sentimental view of the past); present-hedonistic (i.e., pleasure-oriented impulsive attitude toward time and life); present-fatalistic (i.e., hopeless, nihilistic attitude toward life); and future (i.e., striving for future goals). A single word was changed in two items of the scale to increase the relevancy of the measure for older adults (i.e., item 1 "party" was replaced with "socialize"; item 13 "play" was replaced with "leisure"). Sample items include "It is more important for me to enjoy life's journey than to focus only on the destination;" "When I want to achieve something, I set goals and consider specific means for reaching those goals;" "It doesn't make sense to worry about the future, since there is nothing that I can do about it anyway;" "I get nostalgic about my childhood;" and "It takes joy out of the process and flow of my activities, if I have to think about goals, outcomes, and products." Participants rate the degree to which each statement is characteristic of them and upon completion are left with a score on each of the five dimensions. The scale is a validated multidimensional measure of time perspective with good internal consistency (ZTPI-Past Negative, α coefficient = .82; ZTPI-Past Positive, α = 0.80; ZTPI-Present Hedonistic, α = 0.79; ZTPI-Present Fatalistic, α = 0.74; ZTPI-Future, α = 0.77) and test-retest reliability ranging from 0.70 to 0.80 across subscales (Zimbardo & Boyd, 1999), and has been used in cardiac populations (Hamilton et al., 2003). In this study, the

following Cronbach's alpha were calculated for each of the five subscales: ZTPI-Past Negative, $\alpha = 0.90$; ZTPI-Past Positive, $\alpha = 0.77$; ZTPI-Present Hedonistic, $\alpha = 0.74$; ZTPI-Present Fatalistic, $\alpha = 0.75$; ZTPI-Future, $\alpha = 0.81$.

Medical Term Recognition Test (METER). The METER is a brief self-administered measure of health literacy. The test consists of 40 medical words and 30 nonwords, and participants are asked to mark only those items they recognize as actual words. The test takes approximately 2 minutes to complete. Higher scores indicate a greater level of functional health literacy. Scoring is based on the number of medical words correctly recognized with scores ranging from 0 to 40. Sample medical words include "Diagnosis; Potassium; Arthritis" and nonwords include "Abghorral; Inlest; Malories." The METER has been reported to be a valid and reliable self-administered measure of health literacy (Rawson et al., 2010). Internal consistency is reported to be high (α coefficient = 0.93), and it is strongly correlated with the Rapid Estimate of Adult Literacy in Medicine (REALM; $r = 0.74$; Rawson et al., 2010), one of the most commonly used measures of health literacy (Davis et al., 1993). In addition, the METER has been increasingly used to measure health literacy in heart failure populations (Dolansky et al., 2016; Hawkins et al., 2016). Internal consistency (α) in this study was 0.90.

Results

Descriptive Statistics

A total of 202 heart failure patients consented to participate in this study. However, 34 patients did not complete any of the questionnaires following the initial consent process, leaving 168 heart failure patients who participated in the study. The

survey questions were fully completed by the 168 participants such that there were no missing data. The average age of participants was 58.0 years old ($SD = 13.9$) and the sample was 52% female (80 men; 88 women). Forty-three percent of participants were married, whereas single (19%), widowed (19%), and divorced/separated (19%) participants each made up approximately one fifth of the sample. Over half of the sample was either disabled (31%) or unemployed (26%), while about one third reported that they were working full-time (17%) or part-time (14%), or self-employed (5%). Almost half of participants (45%) reported an annual income of less than \$30,000 (5% less than \$10,000) with 20% of participants reporting an annual income of at least \$60,000. Participants were generally well educated (50% with at least a bachelor's degree; 98% with a high school diploma). The majority of participants identified as Caucasian (95%), while the remaining participants identified as African-American (5%). Eight participants chose not to identify their race/ethnicity. Similarly, most participants self-identified as heterosexual (95%) and the remaining participants identified as gay or lesbian (5%) with four selecting not to identify. Over half of the sample identified as Christian (38% Protestant Christian; 24% Roman Catholic), 14% identified as either atheist or agnostic, 5% identified as Buddhist, and 19% selected 'Other' as their religious affiliation. All demographic data are reported in Table 1.

Refer to Table 2 for additional medical information data not present here. The sample included participants with a diverse range of heart failure severity (Class I = 14%; Class II = 24%; Class III = 33%; Class IV = 7%; Not Known = 21%). The median length of time since participants' had received their heart failure diagnosis was five years (19% diagnosed in the past year; 43% in the past 3 years; 71% in the past 7 years). A portion of

participants (15%) reported having lived with heart failure for over ten years. Approximately one quarter of participants (24%) reported having an implantable cardioverter-defibrillator (ICD). A little more than one third (36%) of participants reported that they had a Do Not Attempt Resuscitation (DNR/DNAR) order in their medical chart. Approximately half of participants (49%) reported having an Advance Directive or Living Will on file with their medical providers (2% reported they were not sure). Forty-eight percent of participants reported that they had not spoken with their medical providers about their prognosis. Most participants indicated that they were interested in receiving information about their prognosis (93%) for the purpose of informed decision-making.

Almost all participants (95%) endorsed having at least one other comorbid medical condition. Most participants (67%) reported at least one emergency department admission within the past year (26% with 1 admission; 21% with 2 admissions; 17% with 3 or more admissions; 33% with no admissions). The majority of participants (62%) reported needing to schedule at least one unplanned medical appointment in the past year. Almost one third of participants (30%) reported spending at least one week in the hospital during the past year, and some participants (14%) reported having received cardiopulmonary resuscitation (CPR) in the past. Most participants (62%) estimated their life-expectancy to be greater than one year, whereas sixteen participants (9%) estimated their life-expectancy to be less than one year with 29% reporting that they did not know their life-expectancy. Forty-six percent reported that end of life issues were not relevant to them.

In this sample, almost half of participants (48%) reported that if they were to be hospitalized, they would currently receive the full scope of medical interventions according to their medical chart, with 26% reporting they would receive most medical treatment but not aggressive interventions, such as intubation. Only 17% of participants reported that they would receive comfort care only per their medical chart. However, participants' responses shifted when asked what kind of medical care they would prefer to receive if they were to be hospitalized in the near future (36% preferred full range of interventions; 40% preferred most treatments but no aggressive interventions; 24% preferred to receive only comfort care). In addition to this inconsistency in treatment preferences and reported documentation, most participants (95%) reported a desire to have more information regarding life-sustaining treatments so they can make informed decisions about their future care.

Recruitment Site Differences

Participants recruited from the American Heart Association support group and ResearchMatch were analyzed to determine if there were significant differences in patient characteristics across recruitment sites. The ResearchMatch sample included 125 participants (74%), while 43 participants (26%) were recruited from the American Heart Association support group forum. Neither sample showed disproportionate representation with respect to gender ($\chi^2 = .77, p = 0.38, \phi = 0.07$), sexual orientation ($\chi^2 = .01, p = 0.99, \phi = .01$), ethnicity ($\chi^2 = 2.91, p = 0.23, \phi = 0.13$), marital status ($\chi^2 = 8.38, p = 0.08, \phi = 0.22$), religion ($\chi^2 = 2.90, p = 0.41, \phi = 0.13$), income, $F(1, 166) = 0.01, p = 0.99, d = 0.01$, or heart failure classification ($\chi^2 = 9.43, p = 0.06, \phi = 0.24$).

Significant differences were found with regard to education ($\chi^2 = 20.76, p < .01, \phi = .35$) and employment status ($\chi^2 = 12.15, p < .01, \phi = .34$). The sample recruited from the American Heart Association support forum contained a disproportionately higher number of participants with Bachelor's Degrees ($n = 21$, expected count = 13.3) compared with the ResearchMatch sample. The ResearchMatch sample also contained a disproportionate number of participants who were unemployed ($n = 38$, expected count = 32.7) compared with the American Heart Association support forum sample. There were no significant differences across recruitment samples with respect to uncertainty in illness, $F(1, 166) = 1.06, p = 0.31, d = 0.18$, health literacy, $F(1, 166) = 0.58, p = 0.49, d = 0.18$, time perspective (Past-Negative, $F(1, 166) = 0.28, p = 0.60, d = 0.11$; Past-Positive, $F(1, 166) = 1.50, p = 0.22, d = 0.19$; Present-Hedonistic, $F(1, 166) = 1.13, p = 0.29, d = 0.18$; Present-Fatalistic $F(1, 166) = 0.87, p = 0.35, d = 0.16$; Future, $F(1, 166) = 0.01, p = 0.97, d = 0.01$), or differences in engagement in end-of-life communication behaviors $F(1, 166) = 2.55, p = 0.11, d = 0.28$. Recruitment sample data can also be found in Table 1.

The majority of participants completed the online version of the survey (99%, $n = 166$) with only two participants electing to complete a paper and pencil version. Given the small number of participants who completed the paper and pencil version, analyses to detect group differences were not conducted. However, post hoc analyses were conducted by running the proposed dissertation analyses while excluding the participants who completed the paper and pencil version. The post hoc analyses produced near identical findings to the results presented in proposed analyses section of this dissertation.

Demographic Variables and End-of-Life Communication

Demographic variables were examined in relation to end-of-life communication, as measured by the ACPES-Actions Scale. Participants' age was positively related to end-of-life communication, $r = 0.308$, $p < .001$. In addition, male participants ($M = 12.35$, $SD = 4.15$) reported more end-of-life communication compared to female participants ($M = 9.36$, $SD = 5.25$), $t(166) = 4.058$, $p < .01$, $d = 0.64$. Participants who identified as gay or lesbian ($M = 16.65$, $SD = 1.60$) reported more end-of-life communication compared to participants who identified as heterosexual ($M = 10.38$, $SD = 4.93$), $t(162) = -3.11$, $p < .01$, $d = 1.92$; although, it should be noted that the sample included only eight participants who identified as gay or lesbian.

Group differences in end-of-life communication were found with respect to marital status, $F(3, 164) = 3.91$, $p < .05$, employment status, $F(5, 162) = 10.493$, $p < .001$, and religious affiliation, $F(3, 164) = 4.59$, $p < .01$. Unplanned post hoc group comparisons were conducted for each of these analyses using adjusted p-values via Tukey's method to mitigate the risk of Type I error (Abdi & Williams, 2010). Post hoc comparisons revealed widowed participants ($M = 12.50$, $SD = 4.57$) reported more end-of-life communication compared to separated/divorced participants ($M = 9.00$, $SD = 5.33$; $CI = 0.35 - 6.65$, $p < .05$, $d = 0.71$). In addition, post hoc comparisons revealed that part-time employees ($M = 6.17$, $SD = 4.91$) reported less end-of-life communication compared to participants who were disabled ($M = 11.31$, $SD = 4.82$; $CI = -8.27 - -2.01$, $p < .001$, $d = 1.06$), unemployed ($M = 13.36$, $SD = 3.94$; $CI = -10.41 - -3.98$, $p < .001$, $d = 1.62$), or self-employed ($M = 13.00$, $SD = 3.21$; $CI = -12.01 - -1.66$, $p < .01$, $d = 1.68$). Likewise, full-time employees ($M = 8.57$, $SD = 3.84$) reported less end-of-life communication

compared to participants who were unemployed (CI = -7.86 – -1.73, $p < .001$, $d = 1.23$).

Lastly, post hoc comparisons also showed that Catholic participants ($M = 12.10$, $SD = 4.24$; CI = 0.32 – 5.37, $p < .05$, $d = 0.59$) and Atheists or Agnostics participants ($M = 12.83$, $SD = 3.61$; CI = 0.59 – 6.58, $p < .05$, $d = 0.70$) reported more end-of-life communication compared to Protestant Christian participants ($M = 9.25$, $SD = 5.37$).

There were no differences in end-of-life communication with respect to participant's education level ($F(3, 164) = 2.628$, $p = 0.06$), race ($F(2, 165) = 1.85$, $p = 0.16$), or income ($r = 0.149$, $p = 0.07$).

Demographic Variables and Uncertainty in Illness

Demographic variables were also examined in relation to uncertainty in illness (see Table 1). Participants' age was correlated with uncertainty in illness scores, $r = -0.208$, $p < .01$. In addition, female participants ($M = 45.45$, $SD = 12.66$) reported more uncertainty in illness compared to males ($M = 39.40$, $SD = 10.32$), $t(166) = -3.38$, $p < .001$; $d = 0.53$). Group differences in uncertainty in illness were also found with respect to religious affiliation, $F(3, 164) = 4.76$, $p < .01$, and marital status, $F(3, 164) = 4.16$, $p < .01$. Unplanned post hoc group comparisons were conducted using adjusted p-values via Tukey's method. Atheist or Agnostic participants ($M = 48.50$, $SD = 15.48$) reported more uncertainty in illness compared to Protestant Christian participants ($M = 38.75$, $SD = 10.09$; CI = 2.56 – 16.94, $p < .01$, $d = 0.84$). Participants who were single ($M = 48.00$, $SD = 12.87$) reported more uncertainty in illness compared to married ($M = 41.61$, $SD = 12.01$; CI = 1.51 – 11.27, $p < .05$, $d = 0.51$) or separated/divorced participants ($M = 38.25$, $SD = 12.72$; CI = 4.13 – 15.62, $p < .01$, $d = 0.76$). No differences in uncertainty in illness were found with respect to income ($r = 0.117$, $p = 0.13$), education ($F(3, 164) =$

1.54, $p = 0.21$), race ($F(2, 165) = 1.977, p = 0.06$), sexual orientation ($F(2, 165) = 1.604, p = 0.129$), and employment status ($F(5, 162) = 0.953, p = 0.449$).

Analyses of Study Aims

Correlational Analyses

To investigate the hypotheses that uncertainty in illness (MUIS–Total Score) as well as the five dimensions of time perspective would each be related to engagement in end-of-life communication (ACPES–Action Scale), correlations among these variables were examined. Due to the statistically significant difference in end-of-life communication between male and female participants (see above), post hoc correlations were also conducted for men and women separately. Descriptive statistics for study variables are reported in Table 3 and zero-order correlations are reported in Table 4.

Aim 1

H1. Uncertainty in Illness was not significantly associated with end-of-life communication, $r = -0.102, p = 0.094$. Post hoc analyses were conducted to examine this relationship for men and women separately. For women, uncertainty in illness was associated with end-of-life communication, $r(88) = -0.204, p < 0.05$, but this relationship did not hold true for men, $r(80) = -0.098, p = 0.103$. Uncertainty in illness was also associated with end-of-life communication for participants over the age of 65, $r(56) = -0.498, p < 0.001$. Moreover, uncertainty in illness was associated with end-of-life communication behaviors in the multiple regression analysis noted below.

Aim 2

H2. The present-hedonistic time orientation (ZTPI–Present-Hedonistic subscale) was positively related to end-of-life communication, $r = 0.139, p < 0.05$. The present-

hedonistic time orientation was positively related to end-of-life communication for both men, $r(80) = 0.189, p < 0.05$, and women, $r(88) = 0.173, p < 0.05$, when analyzed separately.

H3. The present-fatalistic time orientation (ZTPI–Present-Fatalistic subscale) was not associated with end-of-life communication, $r = -0.123, p = 0.057$. This relationship was also non-significant for both men, $r(80) = -0.144, p = 0.201$, and women, $r(88) = -0.032, p = 0.768$.

H4. The past-negative time orientation (ZTPI–Past-Negative subscale) was negatively related to end-of-life communication, $r = -0.181, p < 0.01$. The past-negative time orientation was negatively related to end-of-life communication for women, $r(88) = -0.192, p < 0.05$, but was not significant for men, $r(80) = -0.139, p = 0.154$.

H5. The past-positive time orientation (ZTPI–Past-Positive subscale) was not associated with end-of-life communication, $r = 0.068, p = 0.192$. The past-positive time orientation was negatively related to end-of-life communication in men, $r(80) = -0.282, p < 0.01$, but this relationship was not significant in women, $r(88) = 0.169, p = 0.115$.

H6. The future time orientation (ZTPI–Future subscale) was not associated with end-of-life communication, $r = -0.009, p = 0.454$. This relationship was also non-significant for both men, $r(80) = -0.032, p = 0.775$, and women, $r(88) = 0.024, p = 0.824$.

Hierarchical Multiple Regression Analysis for End-of-Life Communication

Statistical Assumptions. Prior to conducting the hierarchical regression, the relevant statistical assumptions were tested. Zero-order correlations between the independent predictors and collinearity statistics (i.e., Tolerance; Variance Inflation Factors) were within acceptable limits and did not reveal an issue with multicollinearity.

The correlations among the predictor variables included in this study (i.e., demographics, uncertainty in illness, dimensions of time perspective, health literacy) were weakly to moderately strong. No univariate outliers were identified across independent predictors and the dependent variable. Likewise, no multivariate outliers were identified within the regression model using multiple statistical indicators of distance (i.e., $D_{\text{Mahalanobis}}$, D_{Cook}), influence (i.e., $Df\text{Beta}$, $Df\text{Fit}$), and standardized residuals. Normal probability plots were used to assess whether predictor variables were from a normal distribution and each variable was examined for skewness and kurtosis (cutoff value was ± 2 ; West et al., 1995). Scatterplots were used to assess linearity. The assumptions of normality, linearity, and homoscedasticity were all satisfied.

Demographic variables that have been identified as being related to end-of-life communication in prior research were included in the analysis in order to control for potential confounding variables. Extant literature has shown that end-of-life communication may be influenced by age (Balboni et al., 2007; Black et al., 2008; Butler et al., 2015; Caralis et al., 1993; Huang et al., 2016; Young, Wordingham, et al., 2017), gender (Black et al., 2008; Butler et al., 2015; Huang et al., 2016), race (Allen et al., 2011; Balboni et al., 2007; Caralis et al., 1993; Huang et al., 2016; Luth, 2016; True et al., 2005), education (Black et al., 2008; Caralis et al., 1993; Sharp et al., 2012), marital status (Butler et al., 2015; Young, Redfield, et al., 2017; Young, Wordingham, et al., 2017), employment status (Huang et al., 2016; Rao et al., 2014), and religious affiliation (Balboni et al., 2007; Black et al., 2008; Sharp et al., 2012; True et al., 2005). Hence, age, gender, race, education, marital status, employment status, and religious affiliation were included in Step 1 of the analysis. Categorical variables were dummy coded so as to be

entered appropriately. Continuous-level predictors were mean-centered and multiplied to form interaction terms to facilitate the interpretation of interaction effects. Data were analyzed with unstandardized data first and produced identical results to the standardized data presented here.

Regression Analysis. A hierarchical multiple regression analysis was conducted to examine the relationships between the independent variables (i.e., uncertainty in illness and the five dimensions of time perspective) as well as interaction effects with end-of-life communication behaviors, after accounting for relevant demographic variables and health literacy (i.e., Hypotheses 7- 11 examined in Step 5). In Step 1 of the regression, demographic variables accounted for 51% of the variance (R^2) in end-of-life communication, $F(19,148) = 9.060, p < 0.001$. Demographic variables entered were participant age, gender, race, education, marital status, employment status, and religious affiliation. See Table 5.

Health literacy was entered in Step 2 of the regression. The addition of health literacy accounted for a significant amount of additional variance ($\Delta R^2 = .012, p < 0.05$) and was associated with end-of-life communication ($\beta = -0.16, p < 0.05$). See Table 6.

In Step 3, uncertainty in illness accounted for a significant amount of additional variance ($\Delta R^2 = .040, p < .001$) in the model. Uncertainty in illness was associated with end-of-life communication and demonstrated a negative relationship ($\beta = -0.241, p < 0.001$), such that when uncertainty in illness was higher, end-of-life communication was lower. See Table 7.

In Step 4, Zimbardo's five dimensions of time perspective (i.e., Present-Hedonistic, Present-Fatalistic, Past-Negative, Past-Positive, and Future) were entered into

the regression. The addition of these variables accounted for a significant amount of additional variance ($\Delta R^2 = .078, p < 0.001$). Two time perspective variables were significantly associated with end-of-life communication. The Past-Negative orientation ($\beta = -0.492, p < 0.001$) and the Present-Hedonistic orientation ($\beta = 0.297, p < 0.001$) were related to end-of-life communication. The Present-Fatalistic orientation ($\beta = -0.081, p = 0.426$), Past-Positive orientation ($\beta = -0.068, p = 0.368$), and Future orientation ($\beta = 0.040, p = 0.658$) were not related to end-of-life communication. See Table 8.

In Step 5, interaction terms for uncertainty in illness with each of Zimbardo's five dimensions of time perspective (i.e., MUIS x Present-Hedonistic, MUIS x Present-Fatalistic, MUIS x Past-Negative, MUIS x Past-Positive, and MUIS x Future) were entered into the regression. The addition of the interaction terms accounted for a significant amount of additional variance ($\Delta R^2 = 0.057, p < 0.001$). Overall, the model accounted for 69% of the variance (R^2) in end-of-life communication, $F(31,136) = 10.743, p < .001$, with a large effect size ($f^2 = 2.26$). There were two interaction effects significantly associated with end-of-life communication (i.e., Past-Positive orientation and Future orientation, see below). In addition, main effects for health literacy ($\beta = -0.185, p < 0.05$), uncertainty in illness ($\beta = -0.298, p < 0.05$), the Past-Negative orientation ($\beta = -0.482, p < 0.001$), and the Present-Hedonistic orientation ($\beta = 0.424, p < 0.001$) remained statistically significant. Regression results including interaction effects are reported in Table 9. Plots of the regression weights were used to interpret each of the statistically significant interaction effects.

H7. The interaction between uncertainty in illness and the Present-Hedonistic orientation was not related to end-of-life communication ($\beta = -0.086, p = 0.342$).

H8. The interaction between uncertainty in illness and the Present-Fatalistic orientation was not related to end-of-life communication ($\beta = -0.085, p = 0.661$).

H9. The interaction between uncertainty in illness and the Past-Negative orientation was not related to end-of-life communication ($\beta = 0.159, p = 0.083$).

H10. The interaction between uncertainty in illness and the Past-Positive orientation was associated with end-of-life communication ($\beta = 0.160, p < 0.05$). As seen in Figure 1, the relationship between uncertainty in illness and end-of-life communication differed as a function of Past-Positive orientation. Participants with both low and high levels of uncertainty demonstrated similar degrees of end-of-life communication when Past-Positive orientation was high. However, for participants with low Past-Positive orientations, end-of-life communication differed depending on participants level of uncertainty in illness. When Past-Positive orientation was low, high levels of uncertainty in illness were associated with reduced end-of-life communication. In other words, there was a stronger negative relationship between uncertainty in illness and end-of-life communication for individuals with a low past-positive orientation.

H11. The interaction between uncertainty in illness and the Future orientation was associated with end-of-life communication ($\beta = 0.255, p < 0.01$). As seen in Figure 2, the relationship between uncertainty in illness and end-of-life communication also differed as a function of Future orientation. Participants with both low and high levels of uncertainty demonstrated similar degrees of end-of-life communication when Future orientation was high. However, for participants with low future orientation, end-of-life communication differed depending on participants level of uncertainty in illness. When future orientation was low, high levels of uncertainty in illness were negatively related to end-of-life

communication. In other words, there was a stronger negative relationship between uncertainty in illness and end-of-life communication for individuals with low future orientation.

To further elucidate the statistically significant interaction effects noted above, post hoc alternative plots were used to examine the relationship between time orientation and end-of-life communication behaviors as a function of uncertainty in illness. Figure 3 examines the relationship between past-positive orientation and end-of-life communication at three different levels of uncertainty in illness (i.e., low, medium, and high). Participants with high uncertainty in illness engaged in relatively few end-of-life communication behaviors unless past-positive orientation was high, whereas participants with moderate levels of uncertainty in illness reported completing end-of-life communication behaviors regardless of their degree of past-positive orientation. Participants with low uncertainty in illness reported relatively high end-of-life communication only when past-positive orientation was low. In other words, past-positive time orientation was positively related to end-of-life communication when uncertainty was high but negatively related to end-of-life communication when uncertainty was low.

Likewise, Figure 4 examines the relationship between future orientation and end-of-life communication at three different levels of uncertainty in illness (i.e., low, medium, and high). Participants with moderate levels of uncertainty in illness reported similar end-of-life communication behaviors regardless of their degree of future orientation. Participants with low levels of uncertainty in illness reported completing more end-of-life communication behaviors when future orientation was low, whereas participants with

high uncertainty in illness reported completing more end-of-life communication behaviors when future orientation was high. Hence, future time orientation was positively related to end-of-life communication when uncertainty was high but negatively related to end-of-life communication when uncertainty was low.

Discussion

The purpose of this study was to examine the psychological mechanisms that bear on patients' engagement in end-of-life communication and empirically evaluate the theoretically proposed relationships between uncertainty in illness, time perspective, and end-of-life communication. Consistent with the extant literature on heart failure patients, the participants in this study describe limited overall engagement in end-of-life communication. Almost half of participants denied having an advance directive documented with their medical providers and a similar portion of participants denied having spoken to their medical providers about their prognosis. This is despite the vast majority of participants expressing interest in receiving more information about their prognosis. Without such information, it is not surprising that almost half of the sample indicated that end of life issues were not relevant to them. This sample of heart failure patients appears typical with respect to many of the characteristics common to heart failure populations. In fact, end-of-life communication in this sample was found to occur at a rate comparable to the average treatment seeking older adult (Sudore et al., 2013). Hence, these findings provide additional empirical support to the research literature demonstrating that the end-of-life care needs of heart failure patients are not being met.

The principal goal of end-of-life communication is to ensure that heart failure patients receive end-of-life care that is in line with their treatment preferences. When

participants were asked about their documented treatment preferences along with their current treatment preferences, their responses generally shifted to less aggressive medical care than what would be provided if they were hospitalized. Despite this discrepancy, the vast majority of participants expressed interest in learning more about life-sustaining treatments. These findings suggest that many heart failure patients may prefer to receive less aggressive medical interventions than what their medical documentation would indicate along with more information to guide their decision-making, which further highlights the importance of quality end-of-life communication.

Uncertainty is widely implicated as a barrier to patient engagement in end-of-life communication for heart failure patients in particular (Ahluwalia & Enguidanos, 2015; Barclay et al., 2011; Garland et al., 2013). Heart failure patients in this study reported experiencing a high degree of illness uncertainty that was within one standard deviation of mean scores found in previous cardiac patient populations (Carleton, Norton, & Asmundson, 2007). To date, the proposition that uncertainty in illness undermines end-of-life communication has been theoretically sound and supported by several qualitative investigations (Etkind et al., 2017; Fry et al., 2016; Im et al., 2019; Paturzo et al., 2016). However, quantitative empirical support for this relationship has yet to be established.

Aim 1. This study sought to confirm the relationship between uncertainty in illness and engagement in activities associated with end-of-life communication. Initial correlational findings suggested that uncertainty in illness was not significantly associated with end-of-life communication. However, post hoc analyses revealed that there is a relationship between uncertainty in illness and end-of-life communication for women, but not for men. There was also a strong negative relationship between

uncertainty in illness and end-of-life communication for participants over the age of sixty-five.

In addition, hierarchical regression analysis revealed that uncertainty in illness was significantly related to end-of-life communication, after controlling for sociodemographic characteristics and health literacy. Heart failure patients reporting more illness uncertainty endorsed less end-of-life communication. This suggests that the initial lack of correlation between uncertainty in illness and end-of-life communication may be due to the existence of multiple confounding factors (e.g., sociodemographic factors, health literacy) that are not being taken into account with a simple correlation. When these confounding variables are controlled for using multiple regression, the relationship between uncertainty in illness and end-of-life communication is able to emerge. This might also explain why the correlation between uncertainty in illness and end-of-life communication is present for women but not men, and also present for older adults specifically. Although findings in support of Aim 1 were ultimately mixed, the results from the regression analysis are consistent with the extant literature implicating uncertainty as a barrier to end-of-life communication, providing limited empirical support to this largely qualitative evidence base (Ahluwalia & Enguidanos, 2015; Barclay et al., 2011; Garland et al., 2013). By demonstrating an empirical relationship between illness uncertainty and end-of-life communication, this study suggests that future research into interventions designed to improve end-of-life communication may benefit from including measurement of illness uncertainty.

Aim 2. Next, this study examined the relationships between dimensions of time perspective and reported completion of end-of-life communication behaviors. Contrary to

expectation, end-of-life communication was not correlated with past-positive, present-fatalistic, or future time orientations. In other words, correlational data did not support the hypothesized positive relationships between end-of-life communication and participants' tendency to hold sentimental views of their past or to strive for future goals. Nor did the data support the hypothesized negative relationship between end-of-life communication and participants' tendency to hold a present focused nihilistic attitude toward life.

Some of these results are inconsistent with previous findings. For example, past-positive time perspective has been positively related to health-promoting behaviors and greater health responsibility in cardiac populations (Hamilton et al., 2003). Interestingly, past-positive time perspective was negatively related to end-of-life communication in men. This may indicate that men specifically that are prone to reminiscing about their past may use nostalgia to avoid engaging in end-of-life communication. Future time perspective has also been associated with a multitude of health behaviors (Gellert et al., 2012; Henson et al., 2006; Rothspan & Read, 1996; Stahl & Patrick, 2012), which runs contrary to the present findings. Nevertheless, Hamilton and colleagues (2003) reported that future time perspective was no longer associated with health-promoting behaviors after controlling for sociodemographic characteristics in a cardiac patient sample. Luth (2016) also found that future time perspective was only related to formal indicators of advance care planning (e.g., advance directive) but not informal end-of-life care discussions when controlling for sociodemographic factors. The end-of-life communication measure in this study (ACPES-Action Scale) includes items related to both formal and informal communication about end-of-life care. Hierarchical regression analysis also bore out a more complicated relationship between end-of-life

communication and the future and past-positive time perspectives. Previous research has not found empirical support for a relationship between the present-fatalistic time perspective and health behaviors, but the present-fatalistic time perspective is associated with greater depression (Zimbardo & Boyd, 1999), which can have a negative impact on cardiac specific health behaviors (Fielding, 1989) as well as prognosis in heart failure patients (Ghosh et al., 2016). However, these findings did not support a negative relationship between present-fatalistic time perspective and end-of-life communication.

It was hypothesized that the present-hedonistic and past-negative time orientations would be negatively related to end-of-life communication. Indeed, participants' tendency to hold aversive views of their past (i.e., past-negative) was negatively associated with end-of-life communication. Although initial correlational analysis suggested that this relationship may have been specific to women, hierarchical regression analysis supported a negative relationship between end-of-life communication and past-negative time perspective after controlling for gender. The past-negative time perspective has been associated with unhappiness, low self-esteem, depressive rumination, and aggression (Zimbardo & Boyd, 1999). While being oriented towards the past may at times be beneficial, the tendency to ruminate about the past may have the additional detriment of stifling end-of-life communication by making more adaptive time perspectives (e.g., present-hedonistic) less cognitively available. It may be the case that heart failure patients who tend to have a negative focus on the past are less likely to bring forth the present focus needed to engage in end-of-life communication nor access as easily the positive memories that can support someone through difficult tasks or discussions.

Contrary to expectation, correlational data revealed a positive association between participants' tendency to have an impulsive attitude toward time and life (i.e., present-hedonistic) and end-of-life communication. This is inconsistent with much of the research conducted in younger adults that has shown the present-hedonistic orientation is associated with a disregard for future consequences through more health-risk behaviors (Keough et al., 1999; Zimbardo et al., 1997). While the present-hedonistic orientation may not be adaptive for younger adults, older heart failure patients for whom mortality has become more salient may be more focused on maximizing positive meaningful experiences and emotional satisfaction, which is consistent with socioemotional selectivity theory (Carstensen et al., 1999). The tendency to respond reflexively with an optimistic outlook may help to encourage end-of-life communication among heart failure patients. This is consistent with previous research showing that a present orientation among the elderly population is positively associated with goal setting and achievement, both positive traits conducive to responsible health behavior (Lennings, 2000). Recent research has also linked a present-hedonistic time perspective to holding a greater number of health goals (Carney & Patrick, 2017), suggesting that a present-hedonistic orientation may enhance motivation to consider factors related to future health in older adults unlike in younger adults. Discussing values and goals concerning the end-of-life may be experienced as rewarding by older adults focused on living each moment in the most fulfilling manner possible as it provides some peace of mind about their future care. Given the tendency of many heart failure patients to be present focused (Gott et al., 2008), capitalizing on this tendency to promote end-of-life communication may be a potential avenue for enhancing end-of-life care.

It should be noted that findings from the regression analysis reinforce the correlational findings noted above, providing further empirical evidence that end-of-life communication may be positively related to present-hedonistic time orientation and negatively related to past-negative time orientation. These variables remained uniquely associated with end-of-life communication even after accounting for the variance attributable to other factors. This is the first empirical evidence that specific dimensions of time perspective within a multidimensional framework may have a unique impact on end-of-life communication.

Aim 3. Lastly, findings from the hierarchical regression analysis suggest that future orientation and past-positive orientation moderate the relationship between uncertainty in illness and end-of-life communication behaviors. For individuals with high levels of uncertainty in illness, the tendency to be nostalgic and hold sentimental views of the past was associated with more end-of-life communication. One explanation for this finding is that a past-positive time perspective may act as a protective buffer against the negative impact of uncertainty in illness on engagement in end-of-life communication. Frankl (1969) suggested that reexamination of one's past leads to a sense of existential satisfaction when faced with mortality. It may be beneficial for heart failure patients who recognize the life-threatening implications of their diagnosis to look to their past as a way to reaffirm their values and the meaning in their lives. In times when there is high ambiguity and confusion surrounding their illness, doing so may help to guide decision-making and provide the solace necessary to discuss end-of-life concerns. However, for individuals with low uncertainty regarding their illness, a stronger tendency to reminisce on the past was negatively associated with end-of-life communication. The tendency to

be nostalgic may function as a way to avoid contemplating and discussing end-of-life concerns when there is little uncertainty to resolve. Hence, depending on the degree of uncertainty in illness experienced, a greater focus on positive aspects of the past may serve as a helpful guide or as an escape when it comes to end-of-life communication.

Likewise, for individuals with high levels of uncertainty in illness, the tendency to be future-oriented and strive to meet future goals was associated with more end-of-life communication. Yet, for individuals experiencing less uncertainty in illness, higher future orientation may hinder end-of-life communication. Similar to a past-positive time perspective, being future oriented may serve as a protective factor for end-of-life communication engagement when uncertainty in illness is high, but may have a negative impact on end-of-life communication when uncertainty in illness is low. Meta-analytic research has shown a strong positive relationship between uncertainty in illness and anxiety related avoidance strategies (Kuang & Wilson, 2017), which may explain why end-of-life communication was found to be the lowest when uncertainty was high and future orientation was low. High future orientation appeared to negate the detrimental effects of uncertainty on end-of-life communication, perhaps by helping heart failure patients manage anxiety-related avoidance. In other words, being prone to seek out information and work towards future oriented goals may encourage heart failure patients to engage in end-of-life communication as a way to reduce discomfort when uncertainty is high. However, high future orientation may have the opposite effect in heart failure patients with low uncertainty regarding their illness. That is, patients experiencing little ambiguity or unpredictability regarding their illness (e.g., patients who have a poor understanding of the progressive terminal nature of heart failure and do not believe end-

of-life concerns are relevant to their situation) may be less inclined to discuss end-of-life concerns when future orientation remains high. Alternatively, for patients with reduced uncertainty due to their being close to death, the tendency to be highly future orientated may create an opportunity for patients to reappraise the smallest amount of uncertainty into possibility, and thereby reducing motivation to engage in end-of-life communication.

Together, these findings indicate that uncertainty in illness and specific dimensions of time perspective may play a role in heart failure patients' engagement in end-of-life communication. This study moves the literature forward by establishing an empirical relationship between illness uncertainty and end-of-life communication. While it may be known that uncertainty is a central aspect heart failure patients' experience, these findings suggest that it exerts a unique influence on patients' willingness to engage in end-of-life communication, beyond other factors such as health literacy. It is also the first to provide evidence that this relationship may be moderated by specific dimensions of time perspective. Despite the negative influence uncertainty may have on heart failure patients' engagement in end-of-life communication, past-positive and future oriented time perspectives appear to be potential protective factors when uncertainty is high. This study also provides preliminary evidence that time perspective, beyond a single dimension of future time orientation, is directly related to end-of-life communication. Specifically, a present-hedonistic time perspective may have a positive influence on end-of-life communication irrespective of uncertainty in illness, whereas a past-negative time perspective may be detrimental. These findings ultimately extend our current theoretical understanding of chronic uncertainty in illness in heart failure by elucidating the specific

ways in which time perspective moderates the impact of uncertainty on end-of-life communication in those with this impairing condition.

There are limitations to this study that warrant consideration. This study employed a within subjects design, which precludes comparison with a control group. Hence, these findings may or may not be specific to patients with heart failure. The sample of participants was recruited online and composed of patients who self-selected to complete a survey on end-of-life issues. This limits generalizability to heart failure patients demonstrating some willingness to engage with the topic. It is unlikely that heart failure patients who decline to engage with material related to end-of-life are adequately represented in this sample as participation entailed some interaction with the topic. This is likely an issue relevant to all end-of-life research, and it is unclear whether conducting this research using an internet-based platform versus an in-person methodology would change participation. Some heart failure patients may be more hesitant to provide open and honest responses to survey questions related to death and dying when completing an internet-based questionnaire preferring instead to discuss the topic in person. On the other hand, completing a survey about end-of-life concerns in private may be more appealing for some heart failure patients. It also has the added benefit of mitigating experimenter effects that could potentially arise if the survey was administered in person.

Heart failure patients lacking in computer literacy or access to the internet may not be represented in this sample given the methodology. Conducting online research in end-of-life populations (Fischer et al., 2012) and older adult populations (Remillard et al., 2014) has traditionally been met with recruitment challenges and generalizability concerns due to difficulties with internet accessibility and proficiency. However, the

growing ubiquity of the internet has likely altered this landscape since these reports were published. The most recent pew research poll on internet usage in the United States indicated that approximately 73% of adults over the age of 65 reported using the internet in 2019 (Pew Research Center, 2019), a statistic that has steadily increased every year since the year 2000. Nevertheless, participants in this study (58) were generally younger than the average heart failure patient at the time of diagnosis (i.e., 77; Senni et al., 1998). This disparity suggests that findings obtained from this convenience sample may not fully generalize to all heart failure patients. This age disparity does not appear to be specific to this study and has been identified as a common methodological issue in heart failure research (Kitzman & Rich, 2010) with the mean age of heart failure research participants being 61 years of age (Heiat et al., 2002). Additionally, recruitment procedures did not allow for collateral confirmation of the medical information reported by participants including official medical diagnoses. Participants were asked to provide specific information regarding their medical history so as to reasonably authenticate that they met criteria for inclusion in the study. Results also relied on self-report data drawn from a single time point, thus findings were subject to participant bias and do not permit causal conclusions to be drawn. In addition, the vast majority of participants in this sample identified as Caucasian, which may limit the generalizability of these findings cross-culturally. Future research in this area would benefit from samples that include greater racial and ethnic diversity. The influence of other factors related to advance care planning outcomes, such as disease specific knowledge, prior exposure to end-of-life issues (e.g., death of a family member), and familiarity with life-sustaining treatments, were not

controlled for in this study. Future research could improve upon these findings by replicating this study while controlling for such factors.

Despite the limitations noted, this study employed reliable and validated measures of each construct being assessed. It also contributes to the end-of-life communication literature in multiple ways. It provides empirical support for the relationship between uncertainty in illness and end-of-life communication in heart failure patients and extends the time perspectives literature by providing evidence of the relationship between end-of-life communication and multiple dimensions time perspective. Additionally, novel findings that indicate the moderating effects of time perspective on the relationship between uncertainty in illness and end-of-life communication provides unique insight into the complex psychological phenomena that influence end-of-life communication. Future research can build on these findings in several ways. Many heart failure patients live for years with heightened uncertainty in illness and appraisal of uncertainty tends to shift over time for those living with chronic conditions (Mishel, 1990, 1999). Hence, understanding how changes in uncertainty appraisal over time impact end-of-life communication should be a priority for researchers. For instance, measuring heart failure patients' personal growth through uncertainty (Mishel, 1999) as well as their capacity to tolerate experiences of uncertainty (Dugas et al., 1997; Freeston et al., 1994) would both provide useful insight into the nuances of uncertainty's influence on end-of-life communication. Individuals less tolerant of uncertainty tend to appraise ambiguous situations or events as threatening (Butler & Mathews, 1983; Russell & Davey, 1993), which suggests that those who are intolerant of uncertainty may have a dispositional resistance to coping with chronic uncertainty in illness. The extent to which heart failure

patients' feelings of uncertainty reduce their desire to have end-of-life discussions may likely be amplified for patients that are intolerant of uncertainty.

Additionally, heart failure patients who avoid end-of-life communication due to illness uncertainty may do so because it evokes anxiety regarding their death. Research with cancer patients has found that higher rates of death anxiety are associated with lower likelihood of having an advance directive on file (Brown et al., 2016) and being less likely to talk about end-of-life concerns (Brown et al., 2014). Furthermore, death anxiety has been broadly associated with reduced end-of-life planning (Carr & Khodyakov, 2007) and connected to lower rates of advance directive completion in heart failure patients (Luth, 2016). Extant literature also highlights the role of time perspective in older adults' experience of death anxiety (Quinn & Reznikoff, 1985; Rappaport et al., 1993). Determining the role of death anxiety in the complex relationships between uncertainty in illness, time perspective, and end-of-life communication is an important next step for future research aiming to enhance end-of-life care in heart failure.

As cases of heart failure rapidly increase each year (Lippi & Sanchis-Gomar, 2020) and expanding technological innovations allow patients to live longer absent of quality of life considerations, the need for improved end-of-life communication has never been greater. While there is growing evidence that disease-specific advance care planning interventions for heart failure improve patient documentation of treatment preferences (Denvir et al., 2016; O'Donnell et al., 2018; Sidebottom et al., 2015), the efficacy of current advance care planning interventions to improve concordance rates between heart failure patients' treatment preferences and the medical care they receive remains uncertain (Nishikawa et al., 2020). Ensuring that medical care is carried out in

concordance with patients' values is the paramount goal of end-of-life communication and an essential part of providing quality healthcare at the end-of-life. Even though advance care planning has been shown to improve these concordance rates broadly (Detering et al., 2010), the few clinical trials using heart failure patients specifically have been met with limited success (Kirchhoff et al., 2012; Malhotra et al., 2020).

Incorporating novel approaches to intervention that integrate illness uncertainty and time perspective may further enhance the precision and personalization of heart failure specific advance care planning interventions. For instance, existing advance care planning interventions may benefit from the inclusion of cognitive components designed to foster past-positive or future orientated time perspectives specifically for heart failure patients who experience high degrees of uncertainty. Such an approach may be particularly useful for heart failure patients who continue to experience high levels of uncertainty even after engaging in advanced care planning interventions aimed at reducing knowledge deficits common among heart failure patients.

Ensuring that heart failure patients' values and preferences are honored at the end-of-life is undoubtedly a complex task. It involves addressing structural barriers to make iterative end-of-life conversations more accessible throughout the illness trajectory, securing frequently updated documentation of patients' goals of care, and greater integration of healthcare providers from across multiple disciplines to help navigate the complex interpersonal dynamics that arise between patients, caregivers, and medical providers when discussing topics as emotion-laden as end-of-life concerns. Yet even with such changes, as this research illustrates, failing to address the intricacies of how individual psychological factors impact engagement in end-of-life communication misses

a vital component to improving end-of-life care for heart failure patients. A deeper understanding of the psychological factors that hinder end-of-life communication is imperative for the development of precise interventions best suited to enhance end-of-life communication for each individual.

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Table 1*Demographic Descriptive Statistics*

<u>Demographics</u>	<u>N</u>	<u>Percent</u>	<u>EOL Communication</u>		<u>Uncertainty in Illness</u>	
			<u>Mean</u>	<u>SD</u>	<u>Mean</u>	<u>SD</u>
Sex						
Male	80	48%	12.35	4.15	39.40	10.32
Female	88	52%	9.36	5.25	45.45	12.66
Sexual Orientation	–	–	–	–	–	–
Heterosexual	156	93%	10.38	4.93	43.13	12.15
Gay or lesbian	8	5%	16.65	1.60	39.01	1.07
Prefer Not To Say	4	2%	14.50	0.55	28.24	4.46
Ethnicity	–	–	–	–	–	–
Caucasian	152	90%	10.55	5.14	41.76	11.07
African American	8	5%	12.50	2.67	34.00	2.14
Prefer Not To Say	8	5%	13.50	0.53	66.47	3.78
Marital Status	–	–	–	–	–	–
Single	32	19%	12.13	3.85	48.00	12.87
Married	72	43%	10.22	5.14	41.61	12.01
Widowed	32	19%	12.50	4.57	43.75	8.56
Separated/Divorced	32	19%	9.00	5.33	38.25	12.72
Religion	–	–	–	–	–	–
Catholic	40	24%	12.10	4.24	44.01	10.32
Protestant Christian	64	38%	9.25	5.37	38.75	10.09
Atheist or Agnostic	24	14%	12.83	3.61	48.50	15.48
Other	40	24%	10.70	5.06	43.60	12.29
Education	–	–	–	–	–	–
High School or Less	20	12%	10.40	5.72	46.26	9.81
Some College	64	38%	9.56	5.19	38.58	11.12
Bachelor's Degree	52	31%	11.54	5.13	42.07	12.95
Graduate Degree	32	19%	12.25	3.04	45.35	11.26
Employment	–	–	–	–	–	–
Full-time	28	17%	8.57	3.84	43.43	14.83
Part-time	24	14%	6.17	4.91	38.17	6.81
Self-Employed	8	5%	13.00	3.21	44.00	3.21
Unemployed	44	26%	13.36	3.94	42.27	11.17
Disabled/Not Working	52	31%	11.31	4.82	43.38	12.53
Prefer Not To Say	12	7%	12.20	4.75	46.00	15.79
Recruitment Sample	–	–	–	–	–	–
ResearchMatch	125	74%	11.14	4.94	42.01	11.87
AHA Support Forum	43	26%	9.74	5.01	44.19	12.21

Note. EOL Communication = ACPES Action Score; Uncertainty in Illness = MUIS Total Score.

Table 2*Health Information Descriptive Statistics*

<u>Medical Information</u>	<u>N</u>	<u>Percent</u>	<u>EOL Communication</u>		<u>Uncertainty in Illness</u>	
			<u>Mean</u>	<u>SD</u>	<u>Mean</u>	<u>SD</u>
Heart Failure Class						
Class I	24	14%	11.83	4.06	35.33	11.43
Class II	40	24%	9.90	6.03	34.60	7.50
Class III	56	33%	11.57	4.51	49.35	11.23
Class IV	12	7%	15.00	1.48	38.67	6.29
Unknown	36	21%	8.44	4.46	47.00	10.74
ICD Implant	–	–	–	–	–	–
Yes	40	24%	9.60	4.71	36.60	8.71
No	128	76%	11.16	5.02	44.44	12.25
Level of Care if Hospitalized	–	–	–	–	–	–
Full Code	80	48%	10.30	4.50	40.95	11.28
Selective Care	44	26%	11.00	5.42	41.36	13.99
Comfort Care	28	17%	13.57	4.58	46.29	10.56
Not Sure	16	9%	7.75	4.64	47.48	9.51
Preferred Level of Care	–	–	–	–	–	–
Full Code	60	36%	9.13	5.02	38.40	8.63
Selective Care	64	38%	10.81	5.10	41.00	12.12
Comfort Care	36	21%	13.22	4.11	50.22	12.25
Not Sure	8	5%	7.05	3.75	48.46	10.52
Relevancy of End of Life Issues	–	–	–	–	–	–
Currently facing them	44	26%	14.55	3.18	38.73	7.91
Likely face them in next year	44	26%	8.82	4.44	51.81	6.30
Not relevant	76	46%	9.74	4.51	38.63	13.14
Not Sure	4	2%	7.56	3.85	43.29	11.64
DNAR Order	–	–	–	–	–	–
Yes	60	36%	13.13	3.70	42.67	13.94
No	96	57%	9.79	5.12	42.50	11.35
Not Sure	12	7%	7.00	4.75	42.66	4.03
Advance Directive	–	–	–	–	–	–
Yes	80	48%	14.40	3.01	43.90	12.94
No	80	48%	7.40	3.86	41.50	11.45
Not Sure	4	2%	3.05	1.25	40.00	4.14
Estimated Prognosis	–	–	–	–	–	–
Greater than 1 year	104	62%	11.31	4.61	38.85	12.45
6 months to 1 year	12	7%	16.70	1.30	41.67	4.03
6 months or Less	4	2%	16.25	1.20	47.00	1.45
Not Sure	48	29%	7.75	4.46	50.49	8.25
Health Literacy	–	–	–	–	–	–
Low Category	12	7%	11.00	2.58	51.67	7.92
Marginal Category	40	24%	13.40	4.28	40.80	11.04
Functional Category	116	69%	9.86	5.09	42.24	12.27

Note. EOL Communication = ACPES Action Score; Uncertainty in Illness = MUIS Total Score.

Table 3*Independent and Dependent Variable Descriptive Statistics*

<u>Measures</u>	Mean	SD	Min	Max	Skewness	Kurtosis
End-of-Life Communication	10.79	4.97	1.0	18.0	-0.24	-1.15
Uncertainty in Illness	42.57	11.96	25.0	70.0	0.35	-0.72
Past Negative Orientation	3.11	0.94	1.4	4.8	-0.02	-1.12
Past Positive Orientation	3.35	0.69	1.4	4.4	-0.59	-0.14
Present Hedonistic Orientation	3.23	0.53	1.9	4.5	0.24	0.31
Present Fatalistic Orientation	2.57	0.65	1.1	3.8	-0.12	-0.65
Future Orientation	3.50	0.59	2.2	4.9	0.16	0.36
Functional Health Literacy	35.12	6.01	15.0	40.0	-1.98	1.86

Note. ($N = 168$). End-of-Life Communication = ACPES Action Score; Uncertainty in Illness = MUIS Total Score; Past Negative Orientation = ZTPI Past-Negative Subscale; Past Positive Orientation = ZTPI Past-Positive Subscale; Present Hedonistic Orientation = ZTPI Present-Hedonistic Subscale; Present Fatalistic Orientation = ZTPI Present-Fatalistic Subscale; Future Orientation = ZTPI Future Subscale; Functional Health Literacy = Meter Total Score.

Table 4*Independent and Dependent Variable Intercorrelations*

<u>Measures</u>	<u>Measures</u>						
	ACP	UII	PN	PP	PH	PF	FO
EOL Communication	–	–	–	–	–	–	–
Uncertainty in Illness	-.102	–	–	–	–	–	–
Past Negative	-.181*	.414**	–	–	–	–	–
Past Positive	.068	-.092	-.088	–	–	–	–
Present Hedonistic	.139*	.158*	.416**	.161*	–	–	–
Present Fatalistic	-.123	.572**	.481**	-.057	.405**	–	–
Future Orientation	-.009	-.166*	-.146	.158*	-.303**	-.368*	–
Health Literacy	-.158*	-.152*	-.140	-.048	-.194*	-.371**	.338**

Note. EOL Communication = ACPES Action Score; Uncertainty in Illness = MUIS Total Score;

Past Negative = ZTPI Past-Negative Subscale; Past Positive = ZTPI Past-Positive Subscale;

Present Hedonistic = ZTPI Present-Hedonistic Subscale; Present Fatalistic = ZTPI Present-

Fatalistic Subscale; Future Orientation = ZTPI Future Subscale; Health Literacy = Meter Total

Score;

* $p < .05$; ** $p < .01$; ($N = 183$)

Table 5*Hierarchical Multiple Regression Analysis for End-of-Life Communication: Model 1*

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	R^2	ΔR^2	F	f^2
<i>Step 1:</i>								
Age	0.179	0.044	0.499	4.079***	0.507	0.507	9.060***	1.028
Gender	0.786	0.868	0.079	0.906				
Race ^a	–	–	–	–				
African American	3.379	1.614	0.145	2.094*				
Prefer Not To Say	-0.513	1.496	-0.022	-0.343				
Education ^b	–	–	–	–				
Some College (2 yrs)	-1.335	1.450	-0.131	-0.920				
Bachelor's Degree	0.659	1.459	0.061	0.452				
≥ Master's Degree	0.782	1.523	0.062	0.513				
Marital Status ^c	–	–	–	–				
Married	-1.620	1.337	-0.162	-1.212				
Separated/Divorced	-2.101	1.379	-0.166	-1.523				
Single	4.466	1.489	0.353	2.999**				
Employment ^d	–	–	–	–				
Part-Time	3.368	1.341	0.237	2.512*				
Self-Employed	-1.638	2.268	-0.070	-0.722				
Disabled	7.090	1.169	0.660	6.065***				
Unemployed	4.661	1.036	0.413	4.499***				
Prefer Not To Say	3.115	2.043	0.162	1.524				
Religion ^e	–	–	–	–				
Protestant	-1.340	0.968	-0.131	-1.385				
Atheist or Agnostic	3.614	1.285	0.255	2.813**				
Buddhist	2.361	2.157	0.101	1.094				
Other	-1.989	1.177	-0.157	-1.690				

Note. Reference Group: ^a Caucasian, ^b High School Diploma or Equivalent, ^c Widowed, ^d Full-time Employment, ^e Catholic

* $p < .05$; ** $p < .01$; *** $p < .001$ ($N = 168$)

Table 6*Hierarchical Multiple Regression Analysis for End-of-Life Communication: Model 2*

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	R^2	ΔR^2	<i>F</i> - Δ	f^2
<i>Step 1:</i>								
Age	0.172	0.044	0.479	3.935***	0.507	0.507	9.060***	1.028
Gender	1.388	0.913	0.140	1.519				
Race ^a	–	–	–	–				
African American	3.097	1.611	0.133	1.922				
Prefer Not To Say	-0.082	1.507	-0.004	-0.054				
Education ^b	–	–	–	–				
Some College (2 yrs)	-1.432	1.438	-0.140	-0.996				
Bachelor's Degree	0.194	1.465	0.018	0.133				
≥ Master's Degree	0.673	1.510	0.053	0.446				
Marital Status ^c	–	–	–	–				
Married	-0.473	1.448	-0.047	-0.326				
Separated/Divorced	-1.458	1.405	-0.115	-1.038				
Single	5.006	1.501	0.396	3.335**				
Employment ^d	–	–	–	–				
Part-Time	4.111	1.381	0.290	2.976**				
Self-Employed	-1.448	2.249	-0.062	-0.644				
Disabled	6.895	1.162	0.642	5.932***				
Unemployed	4.895	1.033	0.434	4.737***				
Prefer Not To Say	3.531	1.150	0.235	1.107				
Religion ^e	–	–	–	–				
Protestant	-0.580	1.035	-0.57	-0.560				
Atheist or Agnostic	4.966	1.449	0.350	3.428**				
Buddhist	3.126	2.173	0.134	1.438				
Other	-1.509	1.191	-0.119	-1.267				
<i>Step 2:</i>								
Health Literacy	-0.130	0.066	-0.157	-1.956*	0.519	0.012	3.926*	1.079

Note. Reference Group: ^a Caucasian, ^b High School Diploma or Equivalent, ^c Widowed, ^d Full-

time Employment, ^e Catholic

* $p < .05$; ** $p < .01$; *** $p < .001$ ($N = 168$)

Table 7*Hierarchical Multiple Regression Analysis for End-of-Life Communication: Model 3*

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>R</i> ²	ΔR^2	<i>F</i> - Δ	<i>f</i> ²
<i>Step 1:</i>								
Age	0.129	0.044	0.359	2.960**	0.507	0.507	9.060***	1.028
Gender	1.085	0.882	0.109	1.231				
Race ^a	–	–	–	–				
African American	2.741	1.522	0.118	1.801				
Prefer Not To Say	-0.433	1.268	-0.052	-0.743				
Education ^b	–	–	–	–				
Some College (2 yrs)	-0.973	1.387	-0.095	-0.701				
Bachelor's Degree	0.497	1.411	0.046	0.352				
≥ Master's Degree	1.092	1.456	0.086	0.750				
Marital Status ^c	–	–	–	–				
Married	-0.383	1.392	-0.038	-0.275				
Separated/Divorced	-2.180	1.365	-0.172	-1.598				
Single	4.798	1.444	0.380	3.323**				
Employment ^d	–	–	–	–				
Part-Time	4.167	1.328	0.294	3.139**				
Self-Employed	0.362	2.217	0.16	0.163				
Disabled	7.512	1.130	0.700	6.649***				
Unemployed	5.561	1.010	0.493	5.508***				
Prefer Not To Say	6.112	2.111	0.317	2.896**				
Religion ^e	–	–	–	–				
Protestant	-1.649	1.036	-0.161	-1.591				
Atheist or Agnostic	5.000	1.392	0.352	3.592***				
Buddhist	2.470	2.096	0.106	1.178				
Other	-1.604	1.145	-0.127	-1.400				
<i>Step 2:</i>								
Health Literacy	-0.144	0.065	-0.174	-2.250*	0.519	0.012	3.926*	1.079
<i>Step 3:</i>								
Uncertainty in Illness	-0.100	0.027	-0.241	-3.654***	0.559	0.040	13.348***	1.268

Note. Reference Group: ^a Caucasian, ^b High School Diploma or Equivalent, ^c Widowed, ^d Full-time Employment, ^e Catholic

* $p < .05$; ** $p < .01$; *** $p < .001$ ($N = 168$)

Table 8*Hierarchical Multiple Regression Analysis for End-of-Life Communication: Model 4*

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>R</i> ²	ΔR^2	<i>F</i> - Δ	<i>f</i> ²
<i>Step 1:</i>								
Age	0.050	0.047	0.140	1.076	0.507	0.507	9.060***	1.028
Gender	0.658	0.847	0.066	0.777				
Race ^a	–	–	–	–				
African American	2.371	1.610	0.102	1.473				
Prefer Not To Say	-1.475	2.122	-0.063	-0.695				
Education ^b	–	–	–	–				
Some College (2 yrs)	-2.169	1.580	-0.212	-1.372				
Bachelor's Degree	-2.029	1.631	-0.189	-1.244				
≥ Master's Degree	-0.927	1.538	-0.073	-0.603				
Marital Status ^c	–	–	–	–				
Married	2.026	1.407	0.202	1.440				
Separated/Divorced	-0.765	1.339	-0.060	-0.571				
Single	4.725	1.421	0.374	3.325**				
Employment ^d	–	–	–	–				
Part-Time	6.231	1.301	0.439	4.788***				
Self-Employed	5.241	2.298	0.225	2.280*				
Disabled	9.761	1.190	0.909	8.202***				
Unemployed	8.444	1.241	0.748	6.803***				
Prefer Not To Say	9.687	2.216	0.554	4.823***				
Religion ^e	–	–	–	–				
Protestant	-2.688	1.035	-0.263	-2.596*				
Atheist or Agnostic	4.018	1.426	0.283	2.817**				
Buddhist	0.136	2.267	0.006	0.060				
Other	-2.379	1.163	-0.128	-2.046				
<i>Step 2:</i>								
Health Literacy	-0.187	0.070	-0.225	-2.670**	0.519	0.012	3.926*	1.079
<i>Step 3:</i>								
Uncertainty in Illness	-0.056	0.021	-0.173	-2.132*	0.559	0.040	13.348***	1.268
<i>Step 4:</i>								
Past Negative	-2.597	0.507	-0.492	-5.118***	0.636	0.078	6.096***	1.747
Past Positive	-0.490	0.542	-0.068	-0.903				
Present Hedonistic	2.786	0.853	0.297	3.265**				
Present Fatalistic	-0.624	0.782	-0.081	-0.798				
Future Orientation	0.338	0.763	0.040	0.443				

Note. Reference Group: ^aCaucasian, ^b High School Diploma or Equivalent, ^c Widowed, ^d Full-time Employment, ^e Catholic

* $p < .05$; ** $p < .01$; *** $p < .001$ ($N = 168$)

Table 9*Hierarchical Multiple Regression Analysis for End-of-Life Communication: Model 5*

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>R</i> ²	ΔR^2	<i>F</i> - Δ	<i>f</i> ²
<i>Step 1:</i>								
Age	0.120	0.048	0.335	2.520*	0.507	0.507	9.060***	1.028
Gender	-0.121	0.904	-0.012	-0.134				
Race ^a	–	–	–	–				
African American	3.111	1.895	0.119	1.696				
Prefer Not To Say	2.946	1.381	0.198	1.054				
Education ^b	–	–	–	–				
Some College (2 yrs)	-3.318	1.853	-0.225	-1.985				
Bachelor's Degree	-1.284	1.934	-0.120	-0.664				
≥ Master's Degree	-0.568	1.625	-0.045	-0.350				
Marital Status ^c	–	–	–	–				
Married	-1.332	1.731	-0.133	-0.770				
Separated/Divorced	-2.730	1.500	-0.216	-1.820				
Single	3.662	1.802	0.290	2.032*				
Employment ^d	–	–	–	–				
Part-Time	4.136	1.295	0.292	3.193**				
Self-Employed	0.509	2.840	0.022	0.179				
Disabled	8.017	1.187	0.747	6.753***				
Unemployed	5.593	1.430	0.495	3.910***				
Prefer Not To Say	4.365	2.629	0.226	1.660				
Religion ^e	–	–	–	–				
Protestant	-2.617	1.363	-0.256	-1.920				
Atheist or Agnostic	3.551	1.639	0.250	2.166*				
Buddhist	-3.573	2.857	-0.153	-1.251				
Other	-2.340	1.215	-0.185	-1.926				
<i>Step 2:</i>								
Health Literacy	-0.154	0.077	-0.185	-2.002*	0.519	0.012	3.926*	1.079
<i>Step 3:</i>								
Uncertainty in Illness	-0.133	0.056	-0.298	-2.010*	0.559	0.040	13.348***	1.268
<i>Step 4:</i>								
Past Negative	-2.544	0.610	-0.482	-4.167***	0.636	0.078	6.096***	1.747
Past Positive	-0.476	0.585	-0.085	-1.092				
Present Hedonistic	3.974	0.902	0.424	4.405***				
Present Fatalistic	-0.374	0.822	-0.049	-0.456				
Future Orientation	0.645	0.877	0.076	0.735				
<i>Step 5:</i>								
Uncertainty x PN ^f	0.070	0.040	0.159	1.747	0.693	0.057	5.102***	2.257
Uncertainty x PP ^g	0.115	0.048	0.160	2.409*				
Uncertainty x PH ^h	-0.071	0.075	-0.086	-0.954				
Uncertainty x PF ⁱ	-0.030	0.069	-0.085	-0.440				
Uncertainty x F ^j	0.192	0.074	0.255	2.614*				

Note. Reference Group: ^a Caucasian, ^b High School Diploma or Equivalent, ^c Widowed, ^d Full-time Employment, ^e Catholic

Abbreviations: ^f Past Negative, ^g Past Positive, ^h Present Hedonistic, ⁱ Present Fatalistic, ^j Future

* $p < .05$; ** $p < .01$; *** $p < .001$ ($N = 168$)

Figure 1

Uncertainty in Illness & End-of-Life Communication Moderated By Past Positive Orientation

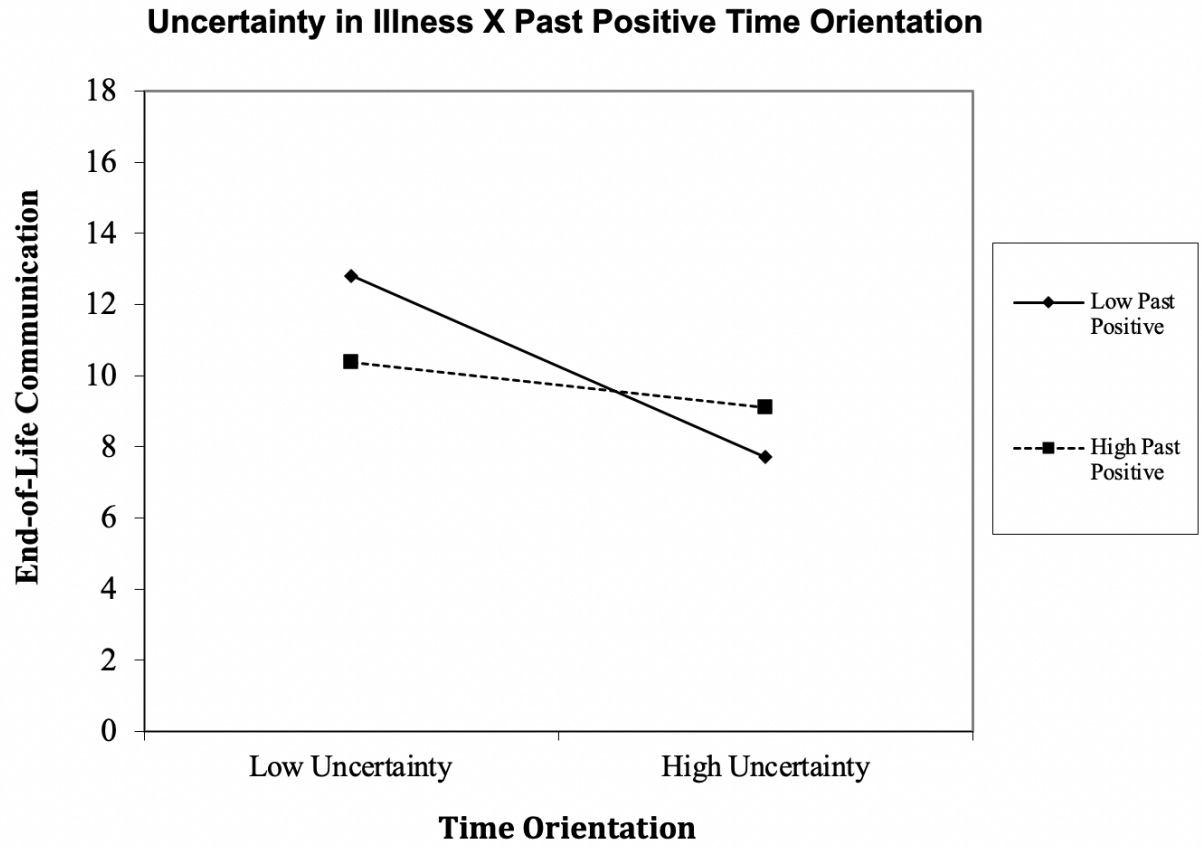


Figure 2

Uncertainty in Illness & End-of-Life Communication Moderated By Future Orientation

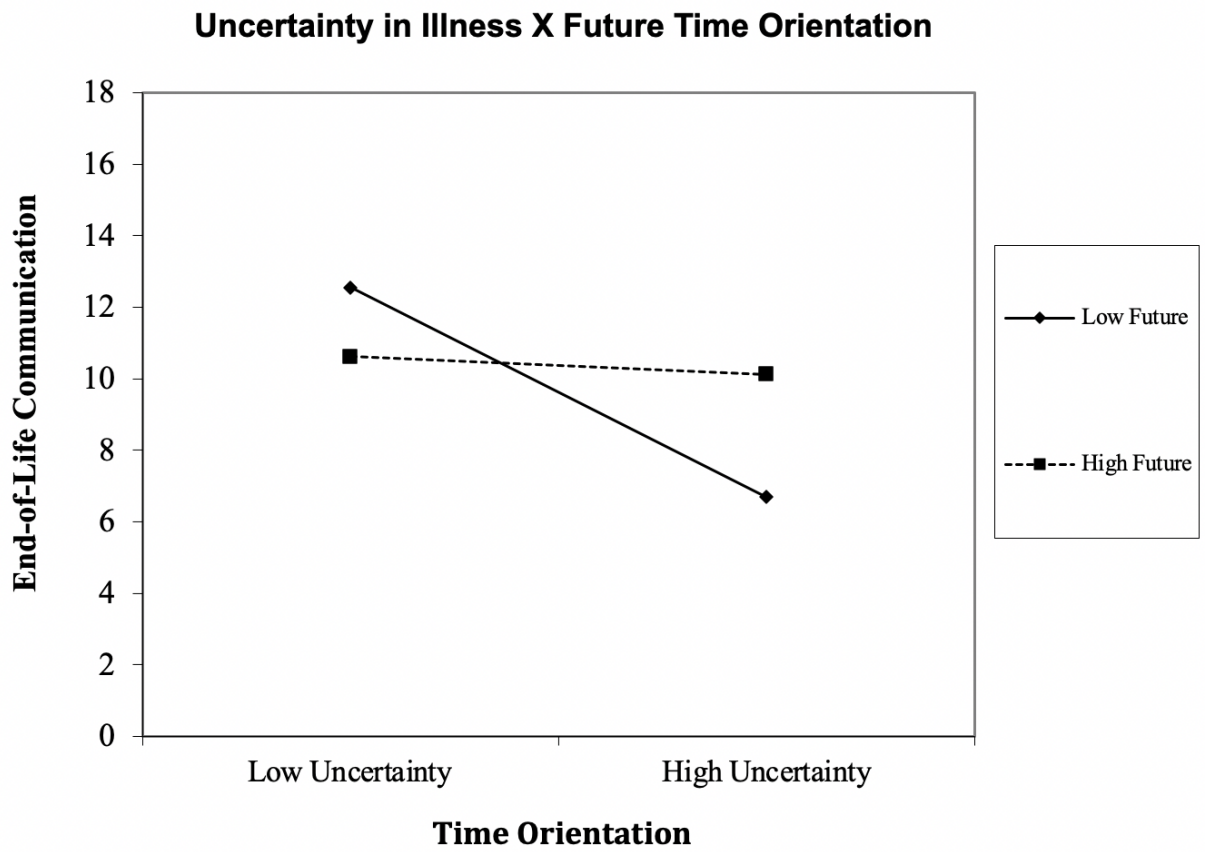


Figure 3

Post Hoc Examination of Interaction Between Uncertainty in Illness & Past Positive Orientation

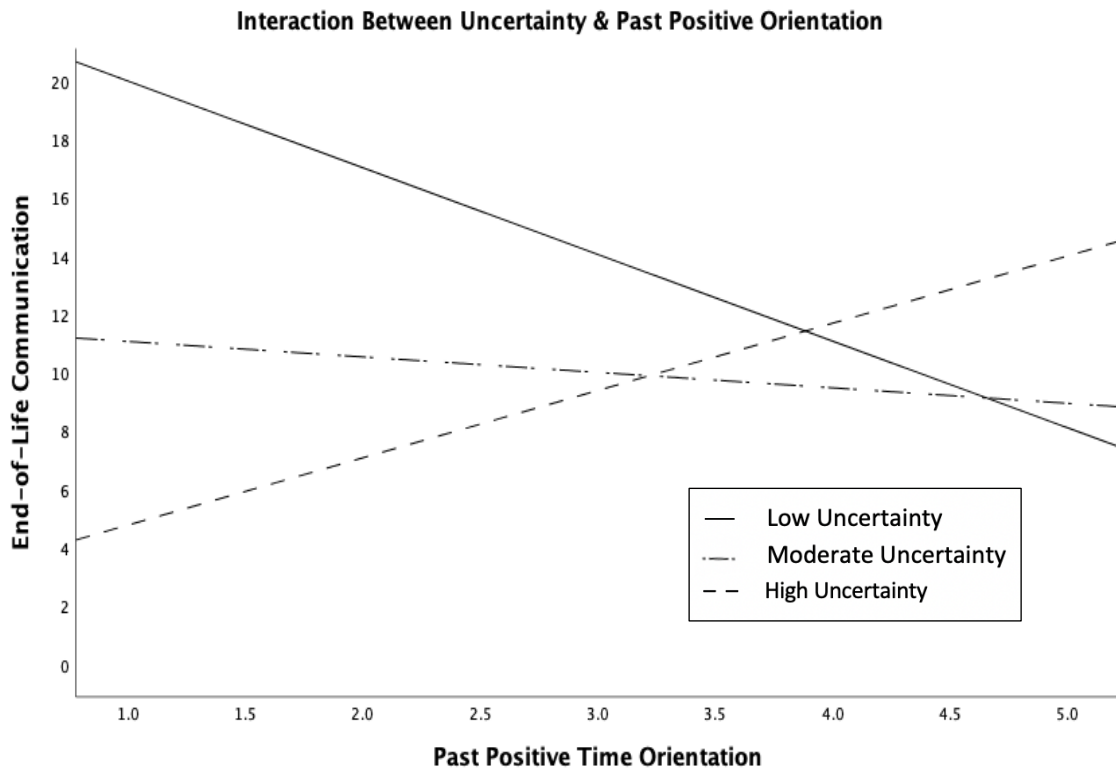
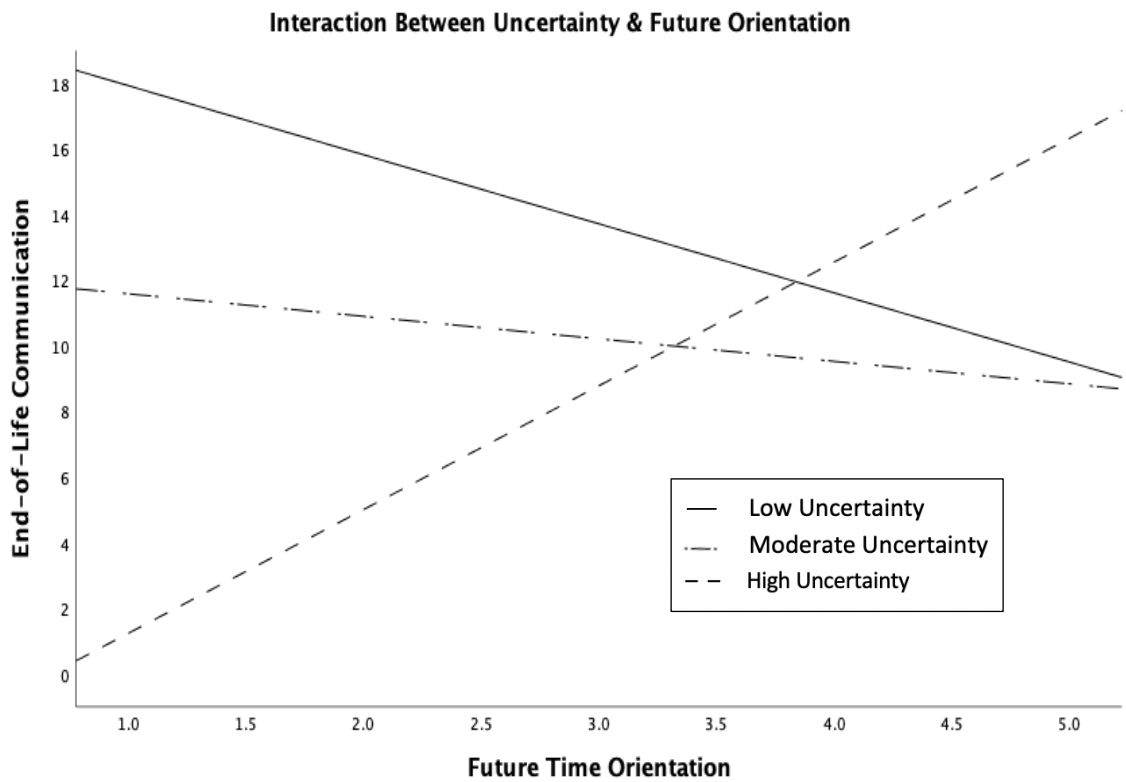


Figure 4

Post Hoc Examination of Interaction Between Uncertainty in Illness & Future Orientation



Appendix A

Diagnostic Status / Medical Information

What are your primary medical/ health conditions?

- | | |
|---|--|
| <ul style="list-style-type: none"> * Arthritis/other musculoskeletal disorders * Asthma * Atrial fibrillation * Cancer * Chronic kidney disease * Chronic pain * Chronic wounds/ulcers that are not healing * COPD, emphysema or chronic bronchitis * Depression (depression, major depression, dysthymia, minor depression) * Dementia/Alzheimer's Disease * Diabetes * Hearing loss | <ul style="list-style-type: none"> * Heart disease (angina, coronary heart disease, Ischemic heart disease) * Heart Failure * High blood pressure * High cholesterol * HIV+/AIDS * Osteoporosis * Stroke * Vision loss/Macular degeneration * Anxiety and Related Disorders (PTSD, Panic, OCD, Generalized Anxiety Disorders) * Schizophrenia or Bipolar Disorder * Substance or Alcohol abuse problems |
|---|--|

If you have been diagnosed with Heart Failure, please tell us what year you were diagnosed.

Which of the following health providers provided the official diagnosis?

- | | |
|---|--|
| <ul style="list-style-type: none"> * Primary Care Physician/General Practitioner * Cardiologist | <ul style="list-style-type: none"> * I don't know * Other (please specify) |
|---|--|

In the past MONTH, how many times have you gone to a hospital emergency department?

In the past MONTH, how many days have you spent in the hospital?

In the past MONTH, how many unplanned medical appointments did you need to make?

Do you have an Implantable Cardioverter Defibrillator (ICD)? * Yes * No

What are your current living arrangements?

- | | | |
|--|---|---|
| <ul style="list-style-type: none"> * Alone * Chronic care facility | <ul style="list-style-type: none"> * Nursing home * With other family | <ul style="list-style-type: none"> * With spouse/partner * Other (please specify) |
|--|---|---|

Where would you prefer to be if you were very sick or near the end of life?

- * Home
- * Hospital
- * Does not matter

Do you have a plan of care in place if you were to have a medical emergency? * Yes * No

Diagnostic Status / Medical Information (continued)...

What factors has your doctor said contributed to your heart failure?

- * Coronary artery disease
- * Hypertension
- * Idiopathic cardiomyopathy
- * Valvular heart disease
- * Arrhythmia (e.g., tachycardia, bradycardia, heart block)
- * Collagen vascular disease (e.g., systemic lupus erythematosus, scleroderma)
- * Endocrine/metabolic disorders (e.g., thyroid disease, diabetes mellitus, pheochromocytoma)
- * Hypertrophic cardiomyopathy
- * Myocarditis
- * Pericarditis
- * Postpartum cardiomyopathy
- * Restrictive cardiomyopathies (e.g., amyloidosis, hemochromatosis, sarcoidosis, other genetic disorders)
- * Toxic cardiomyopathy (e.g., alcohol, cocaine, radiation)

According to your doctor, what is your Functional Heart Failure Classification?

- * Class I: No limitations of physical activity; No heart failure symptoms
- * Class II: Mild limitation of physical activity; Heart failure symptoms with significant exertion; comfortable at rest or with mild activity
- * Class III: Marked limitation of physical activity; Heart failure symptoms with mild exertion; only comfortable at rest
- * Class IV: Discomfort with any activity; Heart failure symptoms occur at rest
- * I Am Not Sure / I Do Not Know

What is the level of care you would prefer to receive if you were hospitalized?

- * FULL TREATMENT: primary goal of prolonging life by all medically effective means.
- * SELECTIVE TREATMENT: goal of treating medical conditions on top of comfort care, but avoids burdensome or aggressive medical procedures (Ex: No Intubation – Breathing tube, but antibiotics and IV fluids are okay).
- * COMFORT-FOCUSED TREATMENT: primary goal of maximizing comfort. No aggressive medical procedures or life-sustaining interventions.

Please indicate the level of care that you would currently receive if you were to be hospitalized?

- * FULL TREATMENT (see above)
- * SELECTIVE TREATMENT (see above)
- * COMFORT-FOCUSED TREATMENT (see above)
- * I do not know

*Have you had CPR before? * Yes * No | What was your most recent ejection fraction?*

*Have you considered what you would like doctors to do if your heart stops beating? *Yes * No*

Diagnosic Status / Medical Information (continued)...

Which situation best describes your preferences about going to the hospital?

- * Transfer me to the hospital in the event of any medical emergency
- * Transfer me only if my comfort needs cannot be met in my current location
- * I do not want to be hospitalized under any circumstance
- * I am not sure
- * I am currently in the hospital

Have you talked with your doctor about how much longer you have to live?

- * Yes
- * No
- * Not sure

What is your understanding of how much longer you have to live?

- * More than 1 year
- * Approximately 1 year
- * Approximately 6 months
- * Less than 6 months
- * Less than 1 month
- * I do not know

Do you want to know about your prognosis or how your illness might progress?

- * Yes
- * No
- * Not sure

How relevant are end of life issues to you?

- * I am currently facing them or have faced them
- * I am likely to face them in the next few weeks to months
- * I will likely face them in the next 6 months
- * I will likely face them in the next year
- * Not relevant

Do you currently have a Do Not Attempt Resuscitation (DNR) order in place?

- * Yes
- * No
- * Not sure

Which of the following best describes your desire for information in order to help you make decisions about whether you want life-sustaining treatments?

- * I would want a lot of information
- * I would want some information
- * I would not want any information
- * I am not sure

Do you currently have an Advance Directive or Living Will on file in your medical chart?

- * Yes
- * No
- * Not sure

Have you spoken to anyone about end of life issues? * Yes * No * Not sure

Who have you spoken to about issues concerning your future care and end of life?

- * Family Member / Close Friend
- * Doctor treating you in hospital
- * Family Doctor
- * Cardiologist
- * Nurse
- * Other (please specify)