A NARRATIVE ANALYSIS OF SPIRITUAL COPING IN INDIVIDUALS WITH TERMINAL HEART FAILURE

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A NARRATIVE ANALYSIS OF SPIRITUAL COPING

IN INDIVIDUALS WITH TERMINAL HEART FAILURE

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ABSTRACT

Approximately 6 million Americans have heart failure with treatment costs estimated at $30.7 billion annually. Those in late stages of the disease experience profound physical, emotional, and spiritual suffering. Spiritual wellbeing has been linked to quality of life as well as mental and physical health in patients with heart failure. While holistic nursing care promotes spiritual coping, barriers exist. Currently, nursing lacks theory to explain spiritual coping processes in patients with heart failure, which leaves nurses ill-equipped to promote spiritual wellbeing in providing care to patients. In this study, I employed open-ended interviewing and narrative analysis techniques to gain a better understanding of spiritual coping over time in patients with terminal heart failure. Participants were recruited from the inpatient cardiovascular wards of an academic, tertiary medical center in the Midwest of the United States. Eligible participants were in stage III or IV heart failure, able to speak English, and able to participate in an extended interview. Purposive sampling was used to create a sample with varied heart failure experiences and diversity in religious and/or spiritual orientation and sociocultural background. Participants were asked to tell me about their spiritual journey. Follow-up prompts focused on describing experiences and strategies that participants associated with spiritual wellbeing. Interviews were read for thematic and structural patterns. The findings were synthesized into a model of spiritual coping comprising

three spiritual coping pathways: heart failure as spiritually integrative, transformative, or disintegrative experience. The specificity of the model of spiritual coping in terminal heart failure offers nurse researchers a structure to support the future development of interventions and aid nurses in promoting quality of life by addressing suffering in patients who have terminal heart failure.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing and Health Studies have examined a dissertation titled "A Narrative Analysis of Spiritual Coping in Individuals with Terminal Heart Failure," presented by Clayton C. Clark, candidate for the Doctor of Philosophy in Nursing, and certify that in their opinion it is worthy of acceptance.

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CHAPTER 1

INTRODUCTION

Heart failure is a significant health problem in the United States, with an estimated 6 million Americans 20 years and older with this condition (Virani et al., 2021). Prevalence is predicted to increase by 46% from 2012 to 2030, resulting in more than 8 million people over 18 years old living with heart failure (Virani et al., 2021). This condition is a substantial financial burden on families and the health system, resulting in an estimated cost of 30.7 billion dollars annually (Virani et al., 2021). As a way of curbing these costs, the integration of palliative care into standard care has been shown to decrease health spending while at the same time relieving the symptom burden and suffering (May et al., 2014; Smith et al., 2014). Individuals with advanced heart failure experience substantial suffering because the disease course is often long and filled with uncertainty (Murray et al., 2004). Individuals often experience distress, anxiety, depression, physical pain, social impairment, and poor overall quality of life (Braun et al., 2016). Palliative care is one way to address the suffering present in heart failure and is a mechanism through which spirituality can be integrated into the total care of the patient. Palliative care is an interdisciplinary approach, combining the expertise of medicine, nursing, social work, chaplaincy, and other allied health professions, which focuses on relieving suffering and improving quality of life through a holistic approach that includes attention toward spirituality and spiritual suffering as well as suffering in other wellness domains (Braun et al., 2016). The holistic and multidisciplinary approach of palliative care makes it a logical practice area in which to address spiritual suffering for patients with advanced heart failure, but the current literature does not provide a theoretical basis for intervention development in the spiritual domain of wellness. Thus, the purpose of

this study is to bolster the theoretical foundations for understanding spiritual coping in patients with terminal heart failure.

Definition of Terms

Spirituality

Spirituality is a complex concept that has been the subject of much debate in nursing literature. Initially, spirituality and religiosity were used interchangeably, but this conceptualization has changed over time (McSherry & Cash, 2004). Spirituality is now conceived of as something separate from religion though also includes religion for some people (McSherry & Cash, 2004; Swinton & Pattison, 2010). Spirituality, as a broader term, encompasses a complexity and variability in understanding that is difficult to capture. Those with more positivist and rationalist views have argued that a lack of conceptual clarity and correspondence with observable reality means that nursing should abandon the term and concept of spirituality in favor of psychological concepts (Paley, 2008). Others contend that most people do have some sense of the spiritual, arguably even atheists, and employ the language liberally (Swinton & Pattison, 2010). Pragmatically, when nurses are freed from the bounds of a particular formal religion, which they are unlikely to share with most of their patients, they can attend to something more abstract, such as spirituality (McSherry & Cash, 2004; Swinton & Pattison, 2010). Definitions for spirituality are variable but tend to focus on four constituent concepts: meaning, purpose, connectedness, and transcendence (Clark & Hunter, 2019). For this study, spirituality will be defined as:

> [A] dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is

expressed through beliefs, values, traditions, and practices. (Puchalski et al., 2014, p. 646)

This definition strikes a middle ground between the positivist who demands conceptual clarity and the pragmatist who recognizes that *spirituality* is a concept best left broad and flexible. It acknowledges the range of functions, purposes, and contexts in which spirituality occurs while still providing a common ground for research and practice on the concept. Other authors reflect a similar definition, referring to meaning, purpose, and connectedness (Baldacchino & Draper, 2001; Blaber et al., 2015). These three sub-concepts are also the most common themes appearing in heart failure specific studies that used a qualitative approach (H. Y. L. Chan et al., 2016; Murray et al., 2007; Paturzo et al., 2016).

Spirituality Sub-concepts

It is important to define the sub-concepts of meaning, purpose, and connectedness to gain a full understanding of spirituality. Meaning and purpose refers to an individual's effort to assign a higher purpose to life, a sense of self-integrity or self-worth, or to positively reinterpret distressing events with a transcendent view (Beagan et al., 2012; de Castella & Simmonds, 2013; Harris et al., 2013; Timmins et al., 2015). Connectedness may include the maintenance of deep relationships with self, family, community, faith, nature, what is significant, or with a transcendent being (Blaber et al., 2015; Grodensky et al., 2015; Lewinson et al., 2015; Puchalski et al., 2014). Connectedness refers to the idea that an individual is part of something greater than themselves or unified with an entity that is outside of themselves in a significant way.

Spiritual Wellbeing

Spiritual suffering is usually measured by the concept of spiritual wellbeing. Spiritual wellbeing is a person's spiritual state of affairs, their perceived status of the spiritual aspect of humanity, including a sense of meaning, purpose, connectedness, and transcendence (Clark & Hunter, 2019).

Spiritual Coping

Spiritual coping as a concept involves both spirituality and coping. Coping is a person's cognitive and behavioral effort to manage either internal or external demands that are interpreted as threatening or distressing (Folkman & Lazarus, 1984). Therefore, spiritual coping may be understood as the cognitive and behavioral efforts to find or maintain meaning, purpose, and connectedness in the face of threatening or distressing situations.

Quality of Life

The World Health Organization (2019) defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." Spiritual wellbeing has been positively correlated with adherence to medical treatment and quality of life and inversely correlated with physical symptom burden, anxiety, and depression (Bekelman et al., 2007; Clark & Hunter, 2019; Mills et al., 2015; Sacco et al., 2014).

Gap in the Literature

The literature in spirituality and heart failure provides substantial descriptive evidence regarding spiritual needs, including what patients feel they want to achieve spiritually and how spiritual wellbeing affects the other aspects of their wellness (Clark & Hunter, 2019). Spiritual wellbeing has been correlated with quality of life and mental health factors in heart

failure. Quality of life captures physical symptoms, psychological symptoms, outlook on life, meaningful existence, and spirituality (Cohen et al., 1995; The World Health Organization, 2019).

A need for meaning and purpose is the most consistently reported theme in the qualitative literature on spiritual needs in advanced heart failure (Clark & Hunter, 2019; Murray et al., 2004; Murray et al., 2007; Ross & Austin, 2015). Participants in qualitative studies examining spirituality in heart failure related a desire to assign cause to their illnesses and find some purpose for their current and future states within the new context of a chronic-terminal illness (Johnson et al., 2007). Another consistently reported theme was connectedness, or the emotional connections people feel to a higher power, other people, or the environment (K. Y. Chan et al., 2016; Heo et al., 2009; Johnson et al., 2007; Murray et al., 2004; Murray et al., 2007; Paturzo et al., 2016; Ross & Austin, 2015). Individuals described a need to maintain relationships with family and friends as well as transcendent connections with a higher power, nature, or humanity (K. Y. Chan et al., 2016; Heo et al., 2009; Johnson et al., 2007; Murray et al., 2004; Murray et al., 2007; Paturzo et al., 2016; Ross & Austin, 2015). Several studies found that people with heart failure were seeking hope from both spiritual resources and their providers (K. Y. Chan et al., 2016; Murray et al., 2004; Ross & Austin, 2015; Westlake & Dracup, 2001).

The focus of palliative care on holistic wellness makes a compelling case for exploring the specialty area as an existing structure in which to include the spiritual dimension in the care for persons who suffer from heart failure. Yet, there is little evidence of the spiritual coping processes or techniques that patients use to resolve states of poor spiritual wellbeing or meet spiritual needs in advanced heart failure. We also do not know whether

patients who engage in spiritual coping obtain relief in their suffering. Hence, any efforts to implement palliative care for patients with advanced heart failure would lack the research-based theoretical foundation for addressing spiritual suffering and facilitating spiritual coping.

The gap in our understanding of spiritual coping is because there is no specific health-oriented theory of spiritual coping in advanced heart failure. There are various religious and theological perspectives on the relationship between spirituality and health. However, the narrowness of religious or theological orientations can make it difficult for practicing nurses to care for the spiritual domain of wellness unless they happen to share the orientation of their patients (McSherry & Cash, 2004). A more general understanding of spirituality and a more theoretically generalizable theory of spiritual coping, outside of a religious or theological framework, liberates nurses to engage patients even when there is a mismatch in spiritual orientations (McSherry & Cash, 2004). There are several adequate descriptions of patients' perceived spiritual needs in advanced heart failure (Clark & Hunter, 2019). Additionally, the theory of self-transcendence, the stress-appraisal-coping model, and other theories have been applied to coping in chronic and terminal illness but not to heart failure (Folkman & Lazarus, 1984; Reed, 2018; Steinhauser et al., 2008). The missing component in the literature is a theory showing how patients with advanced heart failure experience spiritual coping (Clark & Hunter, 2019).

This gap is uniquely significant for patients with advanced heart failure who experience spiritual wellbeing differently than patients with other diseases. Murray et al. (2007) found that spiritual wellbeing in patients with heart failure mirrors the physical pattern of decline, slight improvement, and then further decline. This pattern operates in an

overall declining, cyclical nature (Murray et al., 2007). In cancer, by comparison, spiritual wellbeing declines and spiritual needs increase at transitions in care (Murray et al., 2007). Bekelman et al. (2009) found that, compared to patients with cancer, patients with heart failure tended to have lower spiritual wellbeing. Some patients with heart failure experience deeper isolation and a sense of abandonment by their providers (Murray et al., 2004). The disease course of heart failure may lead to repeated confrontations with end-of-life crises that are not present in the same way within the context of other illnesses. These repeated confrontations with death warrant a focused investigation with heart failure patients to explore their spiritual wellness patterns.

Previously developed and tested interventions to improve spiritual wellbeing such as spiritual inquiry (Ross, et al, 2017), multi-disciplinary palliative care (Rabow, 2004; Gade, 2008), a video/workbook to develop spiritual coping skills (McCauley, 2011), and a psycho-spiritual therapy interview intervention (Steinhauser, 2017). draw on various theoretical sources, including the theory of self-transcendence, the stress-appraisal-coping model, and developmental theories (Folkman & Lazarus, 1984; Reed, 2018; Ross et al., 2017; Steinhauser et al., 2008). None of these interventions utilized a theory specific to spiritual coping in terminal illness or spiritual coping in advanced heart failure. Interventions without well-defined theoretical foundations can result in intervention components that are not specific or matched to the underlying factors capable of producing change and so fail to produce the hypothesized outcomes (Sidani, 2015). Interventions informed by theory have a higher level of effectiveness than those which are not (Painter et al., 2008). To create effective spiritual coping interventions specific to patients with advanced heart failure, it is essential to develop a theory of spiritual coping in heart failure.

Study Purpose, Specific Aim, and Research Question

This dissertation addresses a foundational, descriptive, and theoretical gap in research to understand and address spiritual coping. To do so, there are five chapters including a review of literature and conceptual framework, discussion of methods, findings, and discussion and conclusions.

Given the literature reviewed above, there is a link between spiritual wellbeing and quality of life, mental, physical, and emotional wellbeing. Given such evidence, rigorously developed and tested interventions could affect these outcomes, leading to better treatment for patients with advanced heart failure and reducing healthcare expenditures. This dissertation aims to explore the life narratives of people with advanced heart failure to understand from their perspective the spiritual coping strategies they use and how they relate to spiritual wellbeing. The major question for this study is: What do the illness narratives of people with advanced heart failure reveal about experiences of spiritual coping and spiritual wellbeing? The results will be used to propose a model for spiritual coping in the face of advanced heart failure.

To move the science forward, it is important to fill in the theoretical gaps describing spiritual coping in advanced heart failure. The proposed research question can be answered using a narrative approach. Narratives provide data in the form of storied texts that speakers use to construct meaning for themselves and to convey meaning to the listener. Narratives often contain rich, highly contextualized information about an experience as it unfolds over time. In this study, life narratives were solicited from patients suffering from advanced heart failure with a particular focus on the spiritual coping practices they employed through the course of the disease, including their sense of which practices have been effective and which

have not. The descriptions of spiritual coping provided by participants were synthesized into theoretical propositions based on their patterns of spiritual coping in heart failure. The patterns provide a theoretical foundation for revising existing proposed interventions or building and testing new interventions.

Narrative methods are preferred over grounded theory for the primary analysis approach. Grounded theory is more decontextualized than narrative inquiry in that the text is fragmented and coded based on categories of emerging interest, but narrative studies leave the story intact (Lal et al., 2012). Grounded theory uses the concept as the unit of analysis rather than the story as a whole (Lal et al., 2012). In contrast, narrative inquiry is more contextualized accounting better for change over time, across cultures, and in the individual evolution of a self (Gubrium & Holstein, 2009; Josselson, 2011; Riessman, 2008). While narrative studies tend to include the analysis of the content of a story, they also address these elements of context and the structure or form of the stories as well (Gubrium & Holstein, 2009).

The narrative approach to interviewing and data analysis yields a more holistic understanding of spiritual coping in advanced heart failure than some other qualitative methods like grounded theory might provide. Therefore, the resulting model maintains a holistic view of patients' experiences of spiritual coping in heart failure and provides for a deeper conceptual understanding and the development of conceptual relationships beyond what other qualitative methods might yield. With well-defined concepts and testable relationships, interventions can be developed and tested that are more effective at improving spiritual wellbeing and improving associated quality of life variables.

Theoretical Basis

Qualitative research, including narrative methods, does not construct studies using an *a priori* theoretical framework with an aim toward testing conceptual relationships or a hypothesis (Polit & Beck, 2018). At the outset of a study, qualitative studies tend to incorporate theory as a guiding framework or by using it to explain the philosophical foundations of the chosen method. Qualitative studies may also aim to construct theory inductively (Collins & Stockton, 2018). This dissertation incorporates theory in all three of these ways. Namely, I use theory to provide a conceptual framework, as a basis for my narrative methodology, and as the inductive goal of the research (i.e., to elucidate a theoretical model of spiritual coping in advanced heart failure).

Theory as a Conceptual Framework

The first role of theory in this dissertation concerns the conceptual framework which orients the study in the context of what is known about spirituality and coping. All research, whether inductive or deductive, is informed by some beginning knowledge or theory (Merriam, 2009). I based my initial, tentative understanding of spiritual coping on existing theory and the concept analysis that posits more broadly about the way spirituality functions as a part of wellbeing for seriously ill persons. The theories examined and critiqued in the following pages reflect those I found being used in studies that are included in the review of literature presented in chapter 2. Many other theories might have spirituality components and offer additional insight, but those represented in the following sections appear to have been the ones most engaged within the discussion of spiritual coping in terminal heart failure.

Total Pain Theory

Goebel et al. (2009) suggested total pain theory as a theoretical model for understanding spiritual wellbeing in the context of other palliative care outcomes. Saunders, the original developer of the theory, asserted that pain included physical, psychological, social, emotional, and spiritual elements and that to resolve the phenomenon of pain, multiple interventions should be taken to address each of the elements (Saunders & Baines, 1984). Conceptualizing pain as a condition that affected the totality of a patient's being led clinicians to the multidisciplinary and multifaceted approach of modern hospice that aims to relieve suffering in each of the domains identified in total pain theory, including the spiritual (Clark, 1999). By considering that pain has a spiritual component we can begin to understand why outcomes like quality of life, depression, and anxiety are related to spiritual wellbeing. Within the framework of total pain theory, pain or discomfort is a complex web of interaction between all of the patient's domain components (physical, emotional, spiritual, and social). Therefore, total pain theory awakens the clinician and researcher to the idea that these domains are interconnected and affecting and being affected by one another. Understanding that patients might talk about spirituality in terms of pain also aided my formulation of follow-up interview questions and sensitivity to spiritual content in the narrative data that used pain language rather than the language of meaning, purpose, connection, or transcendence. That total pain theory lacks is a process or prescriptive component. By this, I mean that it does not help clinicians or researchers know where or how to intervene to improve the end outcome. Total pain theory provides a sensitizing lens through which we can view pain more broadly and awakens in us the realization that spiritual wellbeing is an important part of holistic wellness.

Stress Process Model

The stress process model has been used to explain why patients with a terminal illness like heart failure might seek meaning/purpose (Harris et al., 2013). The stress process model is a behavioral science theory that explains how a burdensome situation, through the employment of a coping strategy, can be connected to positive emotions (Folkman, 1997). This model includes the concept of meaning-based coping through which individuals attempt to cognitively reinterpret a distressing situation to assign a positive meaning to the experience (Folkman, 1997). In Harris et al.'s (2013) study researchers utilized a qualitative methodology to assess the nature of meaning-based coping in community-dwelling elders that uncovered themes of God as a provider, relationship with God and social support of their faith community, and the experience of meaning (described in terms of purpose in life and a sense of worth or being needed). The inference was that older adults who were approaching the end of life shifted their focus to meaning-based goals (Harris et al., 2013). The stress process model moves us closer to an explanatory theory of spiritual coping by focusing on one of spirituality's constituent components – meaning. However, as noted above, spirituality is more than meaning in that it also includes purpose, connection, and transcendence. The stress process model which helps to show the shift in coping processes toward a reinterpretation of meaning might be one component of spiritual coping but does not likely represent the whole based on the multicomponent definition of spirituality. The stress process model also lacks some specificity about discrete processes, skills, attitudes, or patterns that produce meaning-based coping and which of these things do not. Though some specificity in this regard did emerge within Harris et al. (2013) it was primarily situated in a Protestant

Christian framework. A more study sample with more diverse spiritual orientations might have added valuable and more generalizable understanding to the stress process model.

Post-traumatic Growth

Post-traumatic growth (PTG) occurs when individuals come through trauma or suffering to eventually recover and exceed their previous level of functioning (Hefferon et al., 2009). Post-traumatic growth can lead to perceived positive changes in self, closer family relationships, changed philosophy in life, a better perspective on life, and a strengthened belief system (Hefferon et al., 2009). In those with serious illness, factors such as social support, coping strategies, and physical and mental health are most highly correlated with PTG (Barskova & Oesterreich, 2009). This concept notes the presence of change in these specified areas but does not explicate a detailed process for how people who are faced with serious illness or death engage in this growth. Thus, we are left with an antecedent of trauma/illness, possible modifying factors like social support, and an outcome of improved functioning, but the concept on its own offers no explanatory process to explain relationships between the antecedents and the outcome.

Salutogenic Model

The salutogenic model begins with the assumption that the human system is inherently flawed and naturally subject to disintegrative processes and eventual death (Antonovsky, 1996). The unnatural course in the salutogenic model is wellness and optimum functioning. The result of the salutogenic paradigm is that health-promoting interventions must actively work against this decay. It is not enough to simply avoid risk or illness, but people must actively work toward health. Pathogenesis, the prevailing model in western medicine, tends to see the human system as naturally well and functional, but subject to

unnatural, external assaults that lead to degeneration and eventual death. This begs questions about what kinds of things promote health rather than what prevents disease. The salutogenic model also sees the human system as physiologically, psychologically, socially, and spiritually inseparable, each domain affecting all others all the time (Antonovsky, 1996). One major construct in this model is the *sense of coherence* defined as "a generalized orientation toward the world which perceives it, on a continuum as comprehensible, manageable, and meaningful" (Antonovsky, 1996, p. 15). The sense of coherence motivates people to cope, feel that challenges are understood, and believe they have the resources to cope, all of which are significant factors moving a person toward wellness (Antonovsky, 1996). Spirituality and its contributing concepts of meaning and purpose are tied closely to this sense of coherence. Antonovsky (1996) conceptualized the sense of coherence as a dependent variable (similar but not synonymous with wellbeing) that would be influenced by previous life experiences. Similar to the post-traumatic growth theory, the salutogenic model provides an outcome, sense of coherence, theoretically linked to spiritual coping but not a process for how that outcome can be modified or improved. One valuable contribution is the idea that the strength of a person's sense of coherence is related to life experiences that occur before the threat to wellness.

Theory of Self-Transcendence

The theory of self-transcendence has been used to explain why persons with terminal illnesses and other experiences of vulnerability seek meaning/purpose. The theory of self-transcendence was developed by Reed (1991) from a deductive reformulation of developmental theories. Reed (1991) suggested that adults continue to engage in developmental processes across the lifespan and that self-transcendence is a developmental

process by which a person expands self-boundaries and shifts away from the immediate to a focus on life perspectives and broader purpose (Reed, 1991). This expansion of boundaries helps an individual to organize new information and challenges in a meaningful way, which leads to a sense of wellbeing and wholeness (Reed, 2018). Boundary expansion may happen intrapersonally, interpersonally, temporally, and transpersonally (Reed, 2018). The directions of expansion concepts, as further explained by Reed (2018), relate to ideas common to those themes expressed in qualitative literature on spirituality in heart failure such as connection in the interpersonal domain and meaning in the interpersonal and temporal domains. The theory of self-transcendence has been applied not only to older adults but to situations in which persons are facing life-threatening experiences and terminal illnesses such as AIDS, breast cancer, and chronic illness (Reed, 2018). Again, the theory of self-transcendence does not specifically address spiritual coping or contextualized issues in terminal heart failure. It did offer a framework for formulating follow-up questions during the interview to examine how narrators related to themselves, others, time, and the transcendent. I asked a few times, what helps you to rise above the difficulties you have described? In addition, the idea that vulnerability is an antecedent to self-transcendent boundary expansion provided a prompt to look for moments of vulnerability in the narratives that triggered spiritual examination and coping.

Theory Comparison

The stress process model and the theory of self-transcendence may provide frameworks for understanding how patients achieve holistic wellbeing in the face of a terminal illness like advanced heart failure. They both point toward the idea that spirituality and wellbeing are not stagnant by dynamic. These theories show that patients can adapt to

challenges and ultimately transcend their immediate condition. The stress process model primarily focuses on coping within a stressful event by including the spiritualty constructs of meaning and purpose but drops the constructs of connectedness and transcendence (Folkman, 1997). One advantage of the theory of self-transcendence over the stress process model is that self-transcendence is conceptually more congruent with the constructs of spirituality; meaning, purpose, connection, and transcendence. Temporal boundary expansion in self-transcendence is defined as integrating one's past and future in a way that has meaning for the present, which also correlates to the constructs of meaning and purpose in spirituality (Reed, 2018). Unlike the stress process model, the theory of self-transcendence includes not only ideas related to the spiritual constructs of meaning and purpose but also connectedness through its concepts of interpersonal and transpersonal boundary expansion, which have to do with relationships with others, the environment, and "dimensions beyond the discernable world" (Reed, 2018).

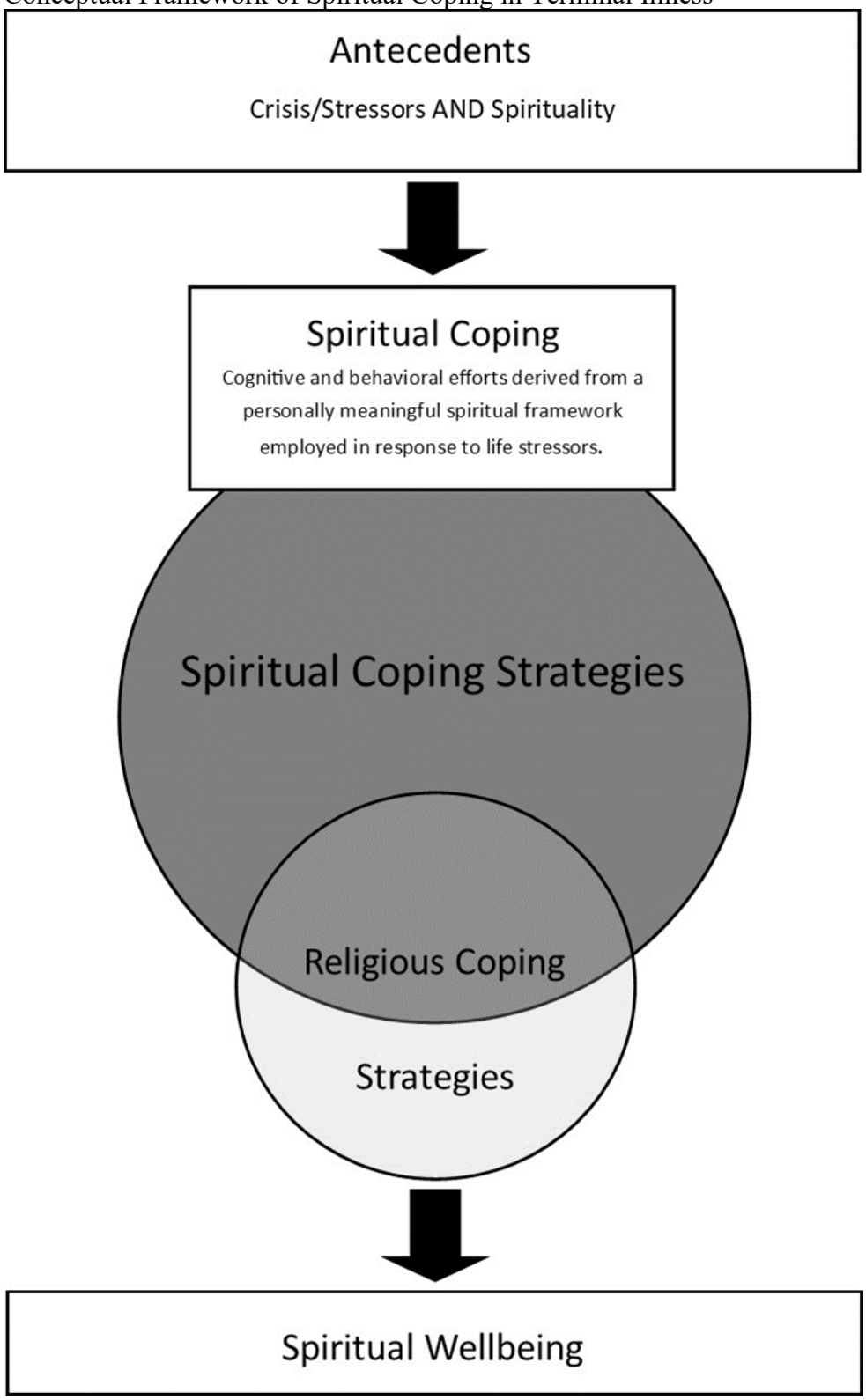
The theories of self-transcendence, stress process model, salutogenic model, and concept of post-traumatic growth provide a foundational theoretical understanding of coping in serious illness, but they lack specificity related to the experience of advanced heart failure and spiritual coping as a distinct process from more global processes of coping. The existing theories broadly describe the multifaceted ways in which people cope with aging and serious illness, with holistic wellbeing as the outcome. They do not address patterns or mechanisms of spiritual coping, any possible role of the health care provider or other outside influence in the process of spiritual coping, or the unique experience of spirituality within the context of heart failure. Being specific about concepts and their relationships in specific contexts facilitates the use of theory in practice (Polit & Beck, 2018). This is why developing a

theoretical framework that focuses specifically on the spiritual aspects of coping and spiritual wellbeing as the primary process outcome in the particular context of heart failure would facilitate the development of effective interventions. Due to the quality of heart failure as a disease process, a theory based on that disease and its experience would promote targeted intervention development. A theory of spiritual coping in terminal heart failure might be re-intersected with the holistic perspective of theories like total pain theory, the stress appraisal coping theory, and the theory of self-transcendence to facilitate practice and research in the holistic framework of palliative care for patients with advanced heart failure.

To improve one aspect of specificity for the conceptual framework in this study, I undertook a concept analysis to delineate spiritual coping from general coping, spirituality, religiosity, and religious coping (Clark & Emerson, 2019). This work used an approach that was based primarily on Walker and Avant's (2011) method but specified the thematic analysis techniques using the guide by Nowell et al. (2017) to draw out defining attributes of spiritual coping from existing literature (Clark & Emerson, 2019). The concept analysis resulted in a conceptual framework of spiritual coping in terminal illness (Figure 1), though it was not specific to advanced heart failure (Clark & Emerson, 2019).

Figure 1

Conceptual Framework of Spiritual Coping in Terminal Illness



The conceptual framework developed in the concept analysis pointed the way to the research question for the current study, informed the interview guide, and provided a reference point for the interpretation of the narrative data. Though the application of a conceptual framework in exploratory qualitative work is discouraged by some methodologists, there is precedent and support for using a conceptual framework to organize a study, identify and develop meanings, connect findings to other literature, and guide the identification of strengths and weaknesses in study design (Collins & Stockton, 2018). Some caution must be exercised though, as the conceptual framework should not be applied rigidly to the emerging data; instead, as I did in this study, the researcher remains attuned to ways in which the data challenge or transcend the framework (Collins & Stockton, 2018). This form of theoretical cross-checking enhances the rigor of the final analysis, as it explicitly links the current study to previous scholarly work on the phenomenon (Polit & Beck, 2018). In this dissertation, I aimed to go beyond simply fitting patients' stories about spiritual coping to a pre-chosen conceptual framework or existing literature. I sought instead to explore the broad range of contextual and relational aspects of spirituality and spiritual coping in reported narratives of advanced heart failure to understand how they connected with what we know from other theories and research and what they offered up as new patterns and insights.

Narrative Inquiry

The theoretical and philosophical literature that underpin my qualitative approach constituted the second role of theory in this dissertation. The choice of approach, narrative inquiry, was driven by the research questions as well as the existing theoretical literature on the phenomenon of interest. Narrative inquiry is an interpretive methodology that developed out of literary criticism (Riessman, 2008). In the human and social sciences, analysts using

narrative inquiry analyze texts holistically, which leads to a finely contextualized case-centered research rather than the more decontextualized theme-centered research of other approaches (Riessman, 2008). The holistic and context-oriented nature of narrative inquiry fits with the underlying constructivist nature of spiritual experience and beliefs.

Narrative inquiry is one of many interpretive research methods that reject the strong positivist view that human behavior can only be studied using methods aimed at discovering an objective "out there" reality (Willis et al., 2007). Instead, the philosophical underpinnings of narrative inquiry are constructivist, meaning that its proponents view understanding and meaning to be constructed in multiple and varied ways based on the perspective and social context of each individual (Creswell, 2014), but narrative inquiry is also influenced by the investigator's interpretation, which is inevitably colored by their own perspectives, experiences, background, and training. The risk of approaching exploratory or any study from a constructivist stance is interpretive bias. The steps described in Chapter 3 were intended to limit or at least identify any interpretive bias I brought to the analysis so that the participants' perspectives remained central. The benefit of a constructivist orientation is that it allows people working in the human sciences to move away from a positivist paradigm in which objective truths are detected and measured using structured methods that control the environment to identify precise relationships to which statistical generalizability can be imputed. On the contrary, narrative inquiry, like other constructivist approaches, assumes that human belief and behavior are complex and not easily categorized, being influenced by the diversity of social, historical, political, and personal contexts in which people live and make sense of their lives (Creswell, 2014). Studying phenomena of this complexity requires

a flexible approach aimed at contextual understanding (McEldowney, 2005; Spector-Mersel, 2010; Willis et al., 2007).

Narratives are stories of experience and can be produced to communicate meaning, morals/ethics, experience, persuasive messages, or to motivate future actions in others (Gubrium & Holstein, 2009; Riessman, 2008). Narrative inquiry takes a unique approach among qualitative methodologies because it uses an open interview structure, allowing the informant to engage in long sections of dialogue about experiences (Riessman, 2008). In this way, the data represent the informant's perspective on reality, usually organized with attention to context and some form of temporal structure (Gubrium & Holstein, 2009). It is important to understand that the philosophical view underlying a narrative approach is that narrative always involves an interpretation (Riessman, 2008). There is no expectation of an exact correspondence to be found between a story and facts in the real world. The point of narrative is to capture how persons perceive their experiences, how they organize their perceptions, feelings, and beliefs. Narrative opens a view of the research participant's inner world, indicating how they understand and psychically manage their experiences. Validating what they report against the *real* world may be extraneous. The focus is on the how and why events are storied, the human relationships within the exchange, and the meaning constructed and conveyed (Riessman & Quinney, 2005). As Barbre and the Personal Narratives Group (1989) stated, "These truths don't reveal the past 'as it actually was,' aspiring to a standard of objectivity. They give us instead the truths of experience" (p. 261). Gee (1985) stressed how narratives are a fitting way to capture human experience since humans naturally construct narratives to make sense of experiences; telling stories is one primary way in which we construct meaning within our world.

Narratives reflect the context of the formative events included in a story and the context in which they are later told. Narratives are co-constructed as a product of interaction between a narrator and a listener/interviewer (Gubrium & Holstein, 2009; Riessman, 2008). Every narrative is performed for a particular audience or context which influences how the story is constructed and what information is included or not included (Gubrium & Holstein, 2009; Riessman, 2008).

Josselson (2011) stated that narratives are traditionally approached holistically or categorically, focused on content or form. Holistic approaches interpret narrative sections both in relation to other sections and to the whole (Josselson, 2011). Categorical approaches use coding strategies, narrowed to sections or words, to compare particular ideas that repeat across narratives (Josselson, 2011). Another important distinction in narrative analysis is the difference between content and form as focal points. Content-focused analysis attends to *what* is said in contrast to form-focused analysis, which concentrates on *how* the narrative is structured (Josselson, 2011; Riessman, 2008). The two are distinct but also overlapping since the structure can act as a kind of content, and content can represent form. Both content-focused and form-focused analyses can be used to discern deeper meanings of a narrative that may not be visible on the surface.

Riessman (2008) divides narrative inquiry approaches into analytical categories: narrative thematic analysis, structural analysis, and dialogic/performance analysis. Narrative thematic analysis focuses on content and uses coding to label ideas in a text that are later developed or consolidated into themes but can maintain a holistic or categorical/comparative approach (Riessman, 2008). Structural analysis focuses on form, how the story is told, and revealing hidden meanings within the text (Riessman, 2008). Dialogic/performance analysis

focuses on what story is performed in the interview and why that particular story is told in the social, cultural, and power-dynamics context in which it is narrated. This dissertation will use techniques of thematic and structural analysis as a way to maintain the holistic nature of narrative inquiry (i.e., to avoid fragmenting the stories into concepts or themes). This analysis approach is also a form of methodological triangulation, using both thematic and structural techniques with the same data, which supports the rigor of the study's conclusions (Riessman, 2008).

It is also important to consider why narrative inquiry was used as the primary method rather than grounded theory or phenomenology. First, grounded theory breaks a text into small, coded units to build concepts and themes (Charmaz, 2011). This method obscures the structural and performative aspects of narrative production and sets aside the holistic approach to the text in favor of a focus on the thematic content and a decontextualized coding process and is appropriate when studying a basic social process with roots in symbolic interactionism. The aim of phenomenology is also similarly decontextualized, that is, to find the *essence* of a lived experience (Wertz et al., 2011) and is used when the question is about experiences of everyday life. Narrative inquiry aims to explore the variety, depth, context, and relational aspects of a lived experience that construct and communicate meaning between people.

To summarize, grounded theory is aimed at eliciting concepts, processes, and relationships; phenomenology aims to discover the essence of a lived experience; and narrative inquiry explores the contextualized meanings of experience as constructed and communicated by the *story* of the lived experience (Wertz et al., 2011). The research question and aims of this study are exploratory and aim at understanding the meanings that

participants would construct related to their spiritual experiences and spiritual coping. As such, the question and aim of the study fit most closely with the aims of narrative inquiry. Because spirituality and spiritual coping are such individualized phenomena, experienced and understood as embedded in a life, exploration of these may most effectively be conducted using a method that preserves context as much as possible. Narrative inquiry preserves that context more completely than grounded theory or phenomenology.

Narrative Inquiry for Theory Development

Theory as an outcome is the third role of theory in this dissertation. Some qualitative methodologies specifically call for theory construction, grounded theory being the most apparent example. However, theory construction can occur within any qualitative methodology (Maxwell, 2013).

Narrative inquiry elicits and documents stories, which raises the question of "What makes it research rather than anthology construction or journalism?" Narrative researchers have been criticized for getting trapped in just telling a good story rather than translating the story into meaningful research (Josselson & Lieblich, 1999; Riessman & Quinney, 2005). Stories can be translated into valuable research when they are interpreted considering the existing literature in a field; they can become transferable when this process results in theory building (Murray, 2009). In one sense, the narrating participants in a study theorize through the cause-and-effect sequencing in their stories and in the meaning construction they formulate through the story-telling process (Riley & Hawe, 2004). Thus, narrators intuitively develop individual, positional explanations about reality as the story is constructed (Riley & Hawe, 2004). Narrative inquiry is aimed at constructing both the explicit and implied meaning present in the stories told. Therefore, narrative researchers are discovering,

organizing, and synthesizing the personal explanations of reality within the stories they collect. Narrative inquiry can be a kind of theory construction that is highly situated within the personal context of the research participants and is also an approach that maintains a holistic rather than decontextualized approach, separating it from grounded theory and other qualitative methods. My dissertation research will adopt these assumptions of personalized explanation construction within the meaning-making process of narrative. The ultimate research aim was to discover and synthesize individually narrated explanations of the heart failure and spiritual experience into a comprehensive theoretical model of spiritual coping in advanced heart failure.

Reflexivity, Positioning, and Power

Reflexivity is "the process of continual internal dialogue and critical self-evaluation of researcher's positionality as well as research process and outcome" (Berger, 2015, p. 220). Reflexivity is an essential part of any interpretive methodology, including narrative inquiry. The dialogic nature and constructivist nature of narrative inquiry necessarily involve the researcher in an intimate interaction with the participant, data, interpretation, and research design. Therefore, it was important for me to establish my own epistemological and ontological positions as well as my unique perspective that inescapably colored the breadth of the research process.

I brought my identifications, values, personal experiences, and assumptions as part of who I am. I am a white male in my thirties, married with three children, currently in a middle-class socioeconomic position. I am privileged to have had the time and resources to earn bachelor's and master's degrees in nursing at a research-intensive university and a post-graduate certificate in health ethics. These credentials have opened doors of practice

experience as a registered nurse in medical-surgical, critical care, physical rehabilitation, mental health, nursing leadership, and nursing education. I came from a two-parent home on a small, very rural, Missouri family farm. I have only ever lived in two places--both in Missouri: my family's farm and a moderate-sized city that is home to a major university. Many in my family have suffered from chronic and terminal illnesses, some with heart failure. I have never personally experienced a life-threatening illness. I am a devout nondenominational Christian (a movement of independent Christian congregations that distance themselves from the creedalism of other Christian communities), heterosexual, and libertarian in my politics. As a result, I tend to take a strong, Bible-oriented moral position but at the same time recognize the individual rights of others to hold beliefs or engage in actions with which I may disagree. I believe strongly in the libertarian non-aggression principle which leads me to aim for persuasion rather than coercion in my interactions with others, especially those with whom I may disagree.

By virtue of my position as a researcher in addition to my socioeconomic status and education, I was situated in a position of comparative power related to my research participants. Due to this power differential, I worked conscientiously to build a trusting rapport with the participants. My experience as a mental health nurse made me well versed in therapeutic communication techniques, which added to my ability to establish rapport. Therapeutic communication in mental health nursing practice emphasizes building trust, unconditional positive regard, and critical self-reflection regarding beliefs, emotional responses, bias, and power dynamics (Boyd, 2018). Including a reflective element in the research memos that I kept during this study provided an opportunity for me to contemplate

my position, biases, and reactions to the participants' narratives during the research process (Birks et al., 2008).

Regarding epistemological and ontological positions, I do believe that there is a single reality that exists but that our human ability and experiences limit our ability to grasp the true substance of that reality. The true reality is bigger, more complicated, and more kaleidoscopically beautiful than any single person can comprehend. As this is the case, I believe that we are each touching only a small part of that true form of reality. In a sense, I believe there are two sorts of "reality" that co-exist. There is the true form of reality which as limited humans we will find impossible to comprehend, and then there is the individually constructed reality. As the saying goes, "perception is reality." I believe this is true in a sense. We have limited perception that feeds our sense of what is real or what is truth. What we can perceive, we construct as our reality. Sometimes, people construct this reality individually, but most often, we construct it collectively. This collective reality exists in groups as small as two people and as large as cultural groups, ethnic groups, or political states. We also must understand that, because our constructed reality is based on our perspective, it is limited, even though it is a shadow of the true form of reality. As humans, we need all the pieces to fit together. When we do not have all those pieces, we fill in the blanks as best we can to resolve the cognitive dissonance that comes with these holes. In this way, each perspective or constructed reality reflects elements of the true reality but can never attain the whole substantive form. Each constructed reality contains elements of truth mixed with elements of vague uncertainty that we have had to fill in to make a logical whole. I see narrative as an important way in which people organize their personal reality in relation to their reality of context through the meaning-making process. People can also place

themselves in another's reality through narrative and learn from a character's experience to modify their cognitive framework about how reality operates (Miller-Day & Hecht, 2013). Therefore, my position is philosophically constructivist, matching the philosophical foundation of narrative inquiry.

Dissertation Organization and Chapter Overview

This dissertation was organized as a single study with embedded manuscripts.

Chapter 1 served as an introduction to the study that included relevant background, significance of the problem, specific aims, research questions, and a theoretical overview.

Chapter 2 presented two finished manuscripts. The first was a previously published review of literature. The second manuscript was an unpublished concept analysis that I used to develop the conceptual framework that guided the dissertation study. In the review of literature, I presented a synthesis of published literature on spirituality, spiritual wellbeing, and spiritual coping in heart failure. In the second part of Chapter 2, I presented the concept analysis, which delineated spiritual coping from religious coping and spirituality within the experience of terminal illness as reflected in the literature. The concept analysis and its resulting process model served as a conceptual framework within which I conducted the narrative inquiry.

Chapter 3 described the methods for the narrative inquiry study. I included a description of the study design, sampling rationale and plan, the plan for data collection and analysis, and protections for human subjects. I concluded Chapter 3 by discussing methods for assuring rigor in qualitative studies and how these criteria were applied to the narrative inquiry.

Chapter 4 is a manuscript of the study presenting the findings. As a research report manuscript, it included some repeated content from previous dissertation chapters, but this content was included so that the manuscript follows the usual expectations for published research reports.

The concluding Chapter 5 articulated a discussion of the study's overall contribution and convergence with other literature as well as conclusions from the project in connection to the research gaps it attempted to fill. Implications for clinical application, future research, and limitations were also provided in Chapter 5.

CHAPTER 2

REVIEW OF LITERATURE

This chapter presents a review of literature and a concept analysis as two finished manuscripts. The first manuscript is a previously published integrated review of literature examining the current literature on spirituality, spiritual wellbeing, and spiritual coping in individuals with advanced heart failure (Clark & Hunter, 2019). Background is given describing the disease course of heart failure. The review findings include descriptive research on spiritual concerns unique to heart failure and a critique of both quantitative and qualitative literature. Two studies that tested proposed interventions are discussed with additional untested interventions recommended throughout the literature. Finally, a discussion of the theoretical literature on spirituality in advanced heart failure is explored. Building upon the findings of this review, implications for research and practice are outlined, which include the potential incorporation of the theory of self-transcendence.

The second manuscript is an unpublished concept analysis on spiritual coping in terminal illness. This concept analysis provides the tentative theoretical framework that was used in this dissertation's development and a starting point for the theoretical model construction that is to occur as the outcome of my work. This analysis starts from the understanding that spiritual coping, as framed within larger theories of coping, shows promise as an influential factor in many aspects of health and wellness. The concept of spiritual coping, however, lacks conceptual clarity that may limit its usefulness in furthering research on the phenomenon. This paper aimed to use an adapted version of Walker and Avant's concept analysis method to distinguish spiritual coping from two similar concepts: spirituality and religious coping. A literature review and thematic analysis yielded defining

attributes, antecedents, consequences, and empirical referents for the concept. These were used to construct a definition of spiritual coping. To further delineate the concept of spiritual coping from similar concepts, a model case, borderline case, related cases, and a pictorial model were provided. A better-delineated concept of spiritual coping supports the research question of this dissertation and provides a tentative foundation for this dissertation's theoretical model construction outcome.

Manuscript One: Spirituality, Spiritual Wellbeing, and Spiritual Coping in Advanced Heart Failure: A Review of Literature

Heart failure is a significant health problem in the United States, with an estimated 5.7 million Americans 20 years and older with this condition (Mozaffarian et al., 2016). Prevalence is predicted to increase by 46% from 2012 to 2030, resulting in more than 8 million people over 18 years old living with heart failure (Mozaffarian et al., 2016). This condition is a substantial financial burden on families and the health system, resulting in an estimated cost of 30.7 billion dollars annually (Mozaffarian et al., 2016). As a way of curbing these costs, the integration of palliative care into standard care has been shown to decrease health spending (May et al., 2014; Smith et al., 2014). Individuals with advanced heart failure experience substantial suffering because the disease course is often long and filled with uncertainty (Murray et al., 2004). Individuals experience distress, anxiety, depression, physical pain, social impairment, and poor overall quality of life (Braun et al., 2016). Palliative care is an interdisciplinary approach that focuses on the relief of suffering and improvement of quality of life (Braun et al., 2016). These effects are said to be achieved through a holistic approach that includes attention toward spirituality and spiritual suffering (Braun et al., 2016). Palliative care practice is limited because few evidence-based

interventions for spiritual care exist. Addressing spiritual wellbeing in this population may aid in the reduction of healthcare spending and, more importantly, relieve some aspects of suffering, leading to improved overall quality of life.

The purpose of this review was to examine the current literature on spirituality, spiritual wellbeing, and spiritual coping in individuals with advanced heart failure. Background is given describing the disease course of heart failure and its historical background, including conceptual definitions. The findings include descriptive research on spiritual concerns unique to heart failure and a critique of both quantitative and qualitative literature. As shown in Appendix A, 30 articles were reviewed, designs of which included the following: one quasi-experimental, 16 correlational-descriptive, one mix-methods, and nine qualitative. There were only two studies that tested proposed interventions, but several interventions were recommended throughout the literature. The studies utilized community-dwelling adults but occurred in varied geographical locations including the U.S., Europe, and China, with a mix of urban and rural. In the included quantitative studies, sample sizes ranged from 23 to 384. Building upon these findings, implications for research and practice are outlined, which include the potential incorporation of the Theory of Self-Transcendence.

Background and Significance

The Disease Course of Heart Failure

Heart failure is a chronic, progressively worsening condition that is characterized by a cluster of symptoms that result from ineffective contraction of the cardiac muscle (Braun et al., 2016). Symptoms may include shortness of breath, activity intolerance, edema, or pain, among many others (Braun et al., 2016). Individuals with advanced heart failure (New York Heart Association classification III or IV) have either “marked limitation of physical activity,

are comfortable at rest, but less than normal activity causes fatigue, palpitation, or dyspnea" or are "unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases" (Dolgin et al., 1994). Sufferers frequently experience cycles with periods of minimal symptoms and periods of exacerbation with a greater symptom burden (Braun et al., 2016). Approximately 50% of all patients with a heart failure-related hospital admission will be readmitted within six months of discharge (Mehra, 2018). These patients will often experience disturbed breathing during sleep, anemia, depression, arrhythmias, renal impairment, severe peripheral or pulmonary edema, and generalized pain (Mehra, 2018). The disease is not only chronic but often terminal with one-year survival rates in end-stage disease (class III or IV) ranging from 6-25% (Braun et al., 2016).

Religion and Spirituality Distinction

Historically, nurses have found it difficult to integrate spiritual interventions as they care for individuals with advanced heart failure due to a lack of conceptual clarity, and inadequate research support (Lewinson et al., 2015). In Western healthcare, the concept of spirituality grew out of the Judeo-Christian religious tradition (McSherry & Cash, 2004). As a result, the concepts of spirituality and religiosity were used synonymously (McSherry, 2000; McSherry & Cash, 2004; Puchalski et al., 2014). This conceptual tie to religion drives many nurses to allocate spiritual care to organized religion, dismissing the profession's assertion that nurses take a holistic view of humans and caring, which would include spiritual care (McEwen & Wills, 2014).

As the literature developed, a distinction emerged between the concepts of spirituality and religiosity (Blaber et al., 2015; Puchalski et al., 2014). However, the most recent

literature continues to reflect some persistent conceptual uncertainty (Blaber et al., 2015; Cooper & Chang, 2016; Lewinson et al., 2015; Selman, Harding, et al., 2011). The terms spirituality and religion are used interchangeably or measured as one combined construct. Instruments intended to operationalize spiritual wellbeing also reflect this uncertainty. Many instruments include elements of religion, specifically Judeo-Christian religion, as a major component (Selman, Harding, et al., 2011; Selman, Siegert, et al., 2011).

Religiosity and spirituality are different concepts, but defining spirituality is difficult due to the individual and contextual nature of spirituality. Religion or religiosity may be defined as a formalized system of beliefs, values, and practices and the measure of adherence to those beliefs, values, and practices (Blaber et al., 2015; Timmins & Neill, 2013). Religion provides some individuals with a formal framework for spiritual exploration and an outlet for spiritual practices (Naghi et al., 2012), whereas spirituality is a personal construct that can exist outside of formalized religion. Therefore, formal religion is sometimes a component of spirituality as a mode of expression but does not reflect the broader concept of spirituality.

Literature Review Methods

Relevant citations were located by searching CINHAL, Ovid databases, PubMed, and Scopus. Inclusion criteria were that the article was peer-reviewed, presented empirical research or theoretical content, and that individuals with heart failure were included in the sample. Review articles were excluded along with citations that were not peer-reviewed. Search terms included spiritual, spiritual care, palliative care, end-of-life care or terminal illness, heart failure, heart disease, or cardiac failure. These searches yielded 1,565 total citations of which 135 were duplicates. After a review of titles and abstracts, 255 citations were retained for full-text review. A full-text review of these searches rendered a final total

of 30 citations to be included in the review after inclusion and exclusion criteria were considered. The retained citations were weak in theoretical content.

Literature Review Findings

The disease course of heart failure yields unique spiritual concerns and patterns of spiritual wellbeing when compared to other diseases. Murray et al. (2007) found that spiritual wellbeing for individuals with heart failure reflects the physical pattern of decline, slight improvement, and then decline, operating in an overall declining, cyclical nature. Comparatively, in cancer, spiritual wellbeing declines, and spiritual needs increase at transitions in care (Murray et al., 2007). Bekelman et al. (2009) found that when compared to individuals with cancer, individuals with heart failure tended to have lower spiritual wellbeing. Individuals with heart failure experience deeper isolation and a sense of hopelessness and abandonment by their providers than those with cancer (Murray et al., 2004). When individuals with heart failure were compared to a general population of individuals without heart failure, those with heart failure demonstrated poorer physical quality of life but greater spiritual wellbeing even after controlling for the reported gender and ethnicity differences in the two samples (Griffin et al., 2007). This suggests that something about the disease may drive persons toward higher levels of spiritual wellbeing. The uniqueness of spirituality for individuals with heart failure necessitates a specific research focus in this population.

The disease course of heart failure affects the spiritual well-being of individuals in unique ways. The extended deterioration and uncertain cyclical pattern of acute decline juxtaposed to moderate improvement, appear to affect the patient's sense of isolation and spiritual wellbeing (Murray et al., 2007). The provider's approach to treatment options,

recommendations, and overall outlook may also be an influencing factor. Yet, the terminal and vulnerable nature of heart failure may also positively influence a person's pursuit of spiritual wellbeing and coping strategies. Certainly, the uniqueness of spirituality for individuals with heart failure necessitates a specific research focus in this population.

Quantitative Literature and Spiritual Wellbeing Correlates

Spiritual wellbeing in heart failure has been correlated to several quality of life and mental health factors. The physical aspect of quality of life is especially important given the cyclical pattern of illness mentioned previously. The spiritual well-being of individuals with heart failure tends to follow the fluctuation of physical symptoms. The degree to which a patient experiences physical symptoms has been inversely correlated to spiritual wellbeing (H. Y. L. Chan et al., 2016; Gusick, 2008). Further, five-year mortality has also been inversely correlated with spiritual wellbeing (Park et al., 2016). Physical wellbeing is, therefore, positively correlated with spiritual wellbeing. One explanatory mechanism may be found in the fact that adherence to medical treatment is also positively correlated with spiritual wellbeing (Alvarez et al., 2016; Chaves & Park, 2016). If spiritual wellbeing improves adherence, then improved adherence may lead to fewer physical symptoms and lower five-year mortality. This is only an assumption, as causality and the direction of relationships cannot be determined from simple correlations. More research is needed to determine if such a causal relationship exists. These correlations do strengthen the philosophical assumption that humans are indivisible beings, that the spiritual and physical are united. If clinicians seek to relieve physical suffering for individuals with advanced heart failure, then spiritual wellbeing must be addressed.

Social support has been positively correlated with spiritual wellbeing and suggested to be a causal factor (Sacco et al., 2014). This correlation lends support to the spirituality sub-concept of connectedness, reflecting the potential for more meaningful interpersonal relationships. Yet, the assertion of causation is unfounded based on the correlational nature of the data. Social support is a factor worthy of additional exploration.

Pertaining to quality-of-life factors, overall quality of life is the most frequently measured and does appear to demonstrate a consistently positive correlation to spiritual wellbeing (Alvarez et al., 2016; Bekelman et al., 2010; Mills, Redwine, et al., 2015; Sacco et al., 2014; Tadwalkar et al., 2014). Though Lum et al. (2016) found no statistically significant correlation between spiritual wellbeing and quality of life, a positive correlation between spiritual wellbeing and quality of life was present at their baseline measurements but not over one year using multivariate analysis. This may be related to the fact that spiritual wellbeing was operationalized as a single item, "Are you at peace?" which may not capture the full context of spiritual wellbeing. The fluctuation in physical symptoms, overall quality of life, and spiritual wellbeing experienced by individuals with heart failure may also have contributed to the inconsistency of the correlation. Westlake et al. (2002) also failed to find a correlation between spiritual wellbeing and overall quality of life. Several limitations affect the reliability of these results. First, the construct validity of the spiritual wellbeing instrument used was reported as being moderately supported (Westlake et al., 2002). The results are also complicated by a small sample size (n = 61) for a correlational study and potential sampling bias due to only a 75% questionnaire return rate (Westlake et al., 2002). Overall, the body of evidence tends to support spiritual wellbeing's correlation with the

overall quality of life. This correlation again verifies the idea that suffering may be relieved by addressing spiritual needs for advanced heart failure individuals.

Spiritual Wellbeing and Mental Health Factors

Regarding mental health factors, Vollman et al. (2009) found a positive correlation between perceived control and existential wellbeing (a concept closely related to spiritual wellbeing). Perceived control is defined as a belief that a person can affect change in internal and external factors to achieve desired outcomes (Vollman et al., 2009). Existential wellbeing, as conceptualized and operationalized in this study, refers to life purpose, satisfaction, and meaningful relationships (Vollman et al., 2009). Existential wellbeing closely reflects the growing conceptualization of spirituality.

Anxiety has also been inversely correlated with spiritual wellbeing (Johnson et al., 2011). Both the faith and meaning/peace subscales of the Functional Assessment of Chronic Illness Therapy Spiritual Wellbeing scale were associated with lower levels of anxiety. Interestingly, Johnson et al. (2011) also measured religious history experiences and found that only negative past religious experiences were associated with higher levels of anxiety. This adds weight to the idea that religion and religiosity are separate concepts from spirituality and that spirituality exerts unique effects on the level of anxiety experienced by individuals.

Anyfantakis et al. (2015) found that spiritual wellbeing was positively correlated with a sense of coherence. Sense of coherence is an attitude viewing internal and external stimuli as predictable and explicable and as challenges worthy of energy and attention (Anyfantakis et al., 2015). It is important to note that the instrument used to measure spiritual wellbeing focuses on religious practices and attendance. This operationalization does not reflect the

conceptual distinction between religiosity and spirituality. The Sense of Coherence Scale used by Anyfantakis et al. (2015) contains a subscale measuring meaningfulness. There is enough conceptual overlap between spirituality and sense of coherence that measurement overlap resulted, thus creating an artificially inflated correlation.

The most frequent correlation reported was between levels of spiritual wellbeing in individuals with heart failure and depression (Anyfantakis et al., 2015; Bekelman et al., 2007; Bekelman et al., 2010; H. Y. L. Chan et al., 2016; Gusick, 2008; Mills, Redwine, et al., 2015; Sacco et al., 2014; Tadwalkar et al., 2014; Whelan-Gales et al., 2009). This demonstrates that spiritual wellbeing and mental and/or emotional suffering are strongly linked. As efforts are made to relieve suffering for individuals with advanced heart failure, the inverse correlation between depression (mental suffering) and spiritual wellbeing lends support to increased efforts to address spiritual needs. At the same time, there is a convincing argument against the strength of this correlation based on measurement overlap (Garssen & Visser, 2016). The assertion is that the Functional Assessment of Chronic Illness Therapy – Spirituality Scale (FACIT-Sp) focuses on questions related to general wellbeing and overall peace, which is not conceptually unique enough to distinguish from depression (or rather lack of depression; Garssen & Visser, 2016). This measurement overlap may artificially inflate the strength of the correlation between the two factors measured (Garssen & Visser, 2016). Bekelman et al. (2010) confirm that there is some measurement overlap between depression items and the FACIT-Sp meaning/peace subscale but that there are also distinct items. The psychometric properties of spiritual wellbeing instruments should be investigated further to determine their validity distinct from measures of depression (Koenig, 2008).

Spiritual Wellbeing Instruments

The previous sections presented concerns regarding instruments purported to measure spiritual wellbeing. In all, 19 instruments have been used to measure spiritual wellbeing in the heart failure population. These instruments have variable degrees of validation and reliability research to substantiate their use. More importantly, the most consistent and strong correlations are maintained when spiritual wellbeing is measured using instruments or subscales that focus on meaning and purpose.

The FACIT-Sp meaning/peace subscale fits closely with the modern conceptual definition of spirituality, specifically the sub-concept of meaning, purpose. Depression, quality of life, and anxiety have been specifically correlated with this subscale independent of other subscales or factors (Bean et al., 2009; Bekelman et al., 2007; Bekelman et al., 2010; Johnson et al., 2011). A statistically significant correlation with the meaning/peace subscale rather than with the FACIT-Sp total or faith subscale substantiates the claim that spirituality as defined by meaning and a sense of peace exerts an effect outside of and despite religion.

Additionally, Bekelman et al. (2010) compared the Ironson-Woods Spirituality Religiousness Index (IW) with the FACIT-Sp. This study found that the IW subscale for sense of peace was positively correlated with the meaning/peace subscale of the FACIT-Sp (Bekelman et al., 2010). In addition, all of the IW was positively correlated with the FACIT-Sp faith subscale (Bekelman et al., 2010). This suggests that the IW reflects faith and religion more than meaning and peace. This is important to note, as the IW total score was not correlated with quality of life or depression compared to the FACIT-Sp meaning/peace subscale which was correlated to both (Bekelman et al., 2010). A correlation present with the FACIT-Sp meaning/peace subscale versus the IW lends credence to the separation of the

religion and spirituality concepts and to the idea that spirituality exerts effects outside of a religious context.

Of note, a single item— "I feel at peace"—was positively correlated with the meaning/peace and faith subscales of the FACIT-Sp and correlated with decreased physical symptoms, improved social support, and improved quality of life (Lum et al., 2016; Steinhauser et al., 2006). This item may be considered a broad measurement of spirituality that incorporates the religious component as well.

Gusick (2008) used the Self-Transcendence Scale (STS) and the Purpose in Life Scale (PIL), finding an inverse correlation with depression. The STS measures transcendence in intrapersonal, interpersonal, transpersonal, and temporal domains (Reed, 2018). These domains reflect the spirituality sub-concepts of meaning, purpose, and connectedness. The PIL contains items that reflect the meaning, purpose sub-concept. This shows that spiritual wellbeing defined in terms of meaning, purpose, and connectedness is tied to mental/emotional wellbeing. Therefore, the ability of clinicians to address meaning, purpose, and connectedness for individuals with heart failure has the potential to alleviate emotional suffering.

Two instruments, the McGill Quality of Life Questionnaire (MQoL) and the Spiritual Wellbeing Scale (SWB), have subscales that operationalize the concept of existential wellbeing (H. Y. L. Chan et al., 2016; Vollman et al., 2009). These instruments conceptualize spiritual wellbeing as having two sub-parts: existential wellbeing and religious wellbeing. Existential wellbeing is defined as a person's purpose in life, interconnectedness with others, and satisfaction with past life events (Vollman et al., 2009). Existential wellbeing, according

to this definition, is a concept that is essentially equivalent to the emerging definition of spiritual wellbeing.

Vollman et al. (2009) found that the existential wellbeing subscale of the SWB scale was positively correlated with perceived control, while the total score of the SWB scale and the religious wellbeing subscale of the SWB scale was not. Perceived control is a person's belief about the degree to which they can control their internal state, influence their environment, and affect behavioral change. This relates importantly to the correlation of the FACIT-Sp meaning/peace subscale with adherence. These two separate correlations provide robust evidence that an individual's degree of meaning, purpose, and connectedness has a relationship to the individual's ability to affect behavior change to address illness. H. Y. L. Chan et al. (2016) likewise found that existential wellbeing demonstrated positive relationships with psychological wellbeing and physical wellbeing. Notably, religious wellbeing did not demonstrate a correlation, suggesting that the religious aspect is not the essential factor of human spirituality.

As an addition to the published content in this literature review manuscript, I would like to further discuss potential measurement overlap between spiritual wellbeing, general wellbeing, and other mental health variables. Spiritual wellbeing may indeed be a component of overall wellbeing, but spiritual wellbeing scales have 25% or more items with similar content to general wellbeing or emotional wellbeing measures (Garssen et al., 2016). In so doing, the correlations between spiritual wellbeing and general wellbeing or mental health factors are often deceptively strong (Koenig, 2008). This is a serious tautological problem that should cause us to temper conclusions about the correlation between spiritual wellbeing

and mental health, general wellbeing, or quality of life and also serve as a compass for improving future studies.

Qualitative Themes

The body of qualitative literature in advanced heart failure has focused on describing the spiritual needs of these individuals. Some individuals described needs for love, peace, happiness, and transcendence (Heo et al., 2009; Lum et al., 2016; Murray et al., 2004). Several studies found that individuals were seeking hope (K. Y. Chan et al., 2016; Murray et al., 2004; Ross & Austin, 2015; Westlake & Dracup, 2001). Ross and Austin (2015) found that this need for hope was expressed as a desire to take a positive outlook on life and "maintain a fighting spirit." Individuals expressed that they wanted the same from their providers; not false hope, but a desire to get the most out of their treatment and to maintain a positive attitude (Ross & Austin, 2015). Individuals interviewed by Westlake and Dracup (2001) expressed a need for hope in a more transcendent respect, looking for ultimate hope, which was often expressed in a religious context. This theme of hope is linked to the concept of life meaning, purpose. Individuals expressing a need for hope are looking for a reason to press on in life. They are seeking a positive purposeful existence for the remainder of their time.

Regret and/or resentment was another repeated theme (Paturzo et al., 2016; Westlake & Dracup, 2001). Individuals experienced regret about past behaviors that they viewed as having caused their heart failure (Westlake & Dracup, 2001). This may symbolize individuals' attempts to make sense of their current illness, to assign meaning. In the case of regret or resentment, which meaning has taken on a negative tone. Westlake and Dracup (2001) assert that this negative meaning is eventually worked out by the patient as

individuals move through a stepwise progression from regret, finding positive meaning, purpose, and finally hope. However, this progression is not justified in the data that they present. It is unknown whether regret and/or resentment are eventually worked out in a positive way. An inability to achieve positive meaning may be the reason individuals with heart failure are often depressed, self-isolating, and hopeless.

The most consistently repeated themes describing spiritual needs of persons with heart failure are meaning and purpose (Hopp et al., 2012; Johnson et al., 2007; Murray et al., 2004; Murray et al., 2007; Ross & Austin, 2015; Westlake & Dracup, 2001). As individuals searched for meaning and purpose, they described efforts to not take things for granted and to realign their priorities (Hopp et al., 2012). They related a desire to assign cause to their illnesses and find some purpose for their current and future states with the new context of a chronic-terminal illness (Johnson et al., 2007; Murray et al., 2004). Individuals were trying to answer the questions "Why?", "Why me?", and "what now?" This ubiquitous search for meaning in the qualitative literature affirms the emerging consensus definition and the correlations present in the quantitative data. Meaning and purpose are important spiritual needs for individuals with advanced heart failure that should be addressed by clinicians who desire to relieve the spiritual suffering present in this population.

The other most consistently repeated theme was connectedness (K. Y. Chan et al., 2016; Heo et al., 2009; Johnson et al., 2007; Murray et al., 2004; Murray et al., 2007; Paturzo et al., 2016; Ross & Austin, 2015). Individuals described a need to maintain relationships with family and friends, as well as transcendent connections with a higher power, nature, or humanity (K. Y. Chan et al., 2016; Heo et al., 2009; Johnson et al., 2007; Murray et al., 2004; Murray et al., 2007; Paturzo et al., 2016; Ross & Austin, 2015). Murray et al. (2004) found

that individuals needed love, which can also be framed as a need for connectedness. Love received and expressed is a relational concept.

Sometimes connections were expressed through formal religion, as in connections with members of a faith group or a connection with a higher power (Johnson et al., 2007; Murray et al., 2004; Murray et al., 2007; Paturzo et al., 2016; Ross & Austin, 2015). Ross and Austin (2015) also found that individuals desired to foster connections with clinicians and found comfort in opportunities to interact positively. Given the social isolation that can occur in advanced heart failure, it is not surprising that connectedness would be a frequently expressed need. The fact that individuals frame this need for connectedness as a spiritual need is important for conceptual clarity and should drive clinicians to seek solutions for the problem.

Proposed Interventions

The current body of literature suggests several potential interventions intended to assist individuals to engage in positive spiritual coping. Chaplaincy has historically been the recommended intervention and continues to be a common suggestion (Attard et al., 2014; Baldacchino, 2008, 2011; Bean et al., 2009; Bekelman et al., 2007; Bekelman et al., 2010; Blaber et al., 2015; Blinderman & Billings, 2015; H. Y. L. Chan et al., 2016; Cooper & Chang, 2016; Ross & Austin, 2015; Tadwalkar et al., 2014; Williams et al., 2016). Chaplaincy services are the standard of care given in current palliative care guidelines (McCusker et al., 2013). The cited authors suggested the integration of chaplaincy services into the care team without justification for its effectiveness. The focus on chaplaincy as the primary intervention for spiritual needs in many cases maintains the bias towards a Judeo-Christian religious orientation. This religious orientation leaves behind those who have

spiritual needs but subscribe to other religious traditions or do not subscribe to any organized religion.

Life review has also been suggested as a potential intervention (K. Y. Chan et al., 2016; Oates, 2004; Steinhauser et al., 2008; Westlake et al., 2008). This intervention is targeted at helping individuals to work through the meaning-making process to achieve a positive view of past and present life events (Steinhauser et al., 2008). Life review was specifically tested in a case study by K. Y. Chan et al. (2016) and a correlational design by Steinhauser et al. (2008). The Chinese patient in the case study was subjected to several interventions in addition to life review and did see improvement in physical, emotional, and spiritual wellbeing (K. Y. Chan et al., 2016). Of course, the nature of a case study design and sociocultural context make it difficult to generalize these results. Though Steinhauser et al. (2008) used life review as an intervention, these authors did not specifically measure spiritual wellbeing, but they did find improvement in several mental health and physical wellbeing domains. Currently, the literature does not fully support life review as an effective intervention to address spiritual needs in advanced heart failure. It may prove useful to address the meaning and purpose domains; even so, it will need to be paired with an intervention to address the connectedness domain of spiritual wellbeing.

Thus far, the reviewed literature has focused on describing the phenomenon of spirituality and spiritual wellbeing. These descriptions and correlates are important but do not yield prescriptive interventions to address the spiritual needs identified. To drive the literature to the point of intervention testing, it is important to describe potential spiritual coping strategies that individuals use as they address the threats to spiritual wellbeing that they are confronted with in heart failure.

The literature does indicate some patient-generated suggestions for interventions. Ross and Austin (2015) asked individuals to provide suggestions for the spiritual needs that they revealed in qualitative interviews. Individuals focused a great deal on meeting practical care needs (coordinating care, getting medication, etc.), but regarding spiritually related needs, individuals suggested provider home visits, visits from volunteers, and for healthcare providers to generally offer a supporting attitude (Ross & Austin, 2015). These individuals were heavily focused on the need for social interaction and social support related to the connectedness domain of spirituality. Whelan-Gales et al. (2009) used the Spirituality Practices Checklist and tabulated the frequency that each practice was selected among the sample. There are two problems with this approach. First, a checklist has the potential to be restrictive; individuals may use practices not listed that more effectively address their spiritual needs. Secondly, many of the items on the provided checklist were either associated with Judeo-Christian religious practices or were so broad that they may not relate to a person's spiritual wellbeing at all, but their psychological wellbeing.

There is a paucity of literature describing, applying, or testing theoretical models for spiritual coping in advanced heart failure. The stress process model is a psychology and/or behavioral science theory that explains how a burdensome situation can produce positive emotions by employment of a coping strategy (Folkman, 1997). Parts of the stress-process model were tested by Bean et al. (2009) and Chaves and Park (2016) who correlated greater levels of spiritual wellbeing with approach coping. Approach coping is a style in which persons consciously use emotional responses and processing to address distressing situations positively. The stress process model also includes the concept of meaning-based coping

through which individuals attempt to cognitively reinterpret a distressing situation to assign a positive meaning (Folkman, 1997).

Literature Review Conclusions and Discussion

Overall, the literature does show correlations between spirituality and several mental health and quality of life factors. These correlations provide evidence that spiritual wellbeing influences the suffering experienced by individuals with advanced heart failure. Further, when spirituality is operationalized as meaning, purpose, and connectedness, significant correlations exist independent of other operationalized factors.

Many of the gaps which exist in the quantitative literature stem from conceptual ambiguity reflected in the operationalization of spiritual wellbeing. The wide variation in conceptualization and subsequent operationalization of spirituality and spiritual wellbeing makes comparing various studies difficult. Many instruments include strong elements of Judeo-Christian religion that are inconsistent with the broader consensus definition. Instruments should be scrutinized for content validity considering the emerging conceptual definition of spirituality.

The qualitative literature provides a substantial body of descriptive evidence related to the spiritual needs expressed by individuals with advanced heart failure but does not address other aspects of the phenomenon. Specifically, the qualitative literature offers little evidence to describe the processes or techniques that individuals use to resolve spiritual distress, to meet the needs expressed. The literature also does not provide evidence for whether individuals who do engage in processes to address spiritual needs do so effectively. Some claim to have elucidated such a process but fail to provide adequate support (Westlake & Dracup, 2001). Individuals most frequently expressed needs for meaning, purpose, and

connectedness. This would suggest that these domains of spirituality represent the most substantial areas of need and are domains on which future descriptive and intervention research should focus. The repetitive expression of meaning, purpose, and connectedness also lends to the validity of the emerging consensus definition that sets aside religion in favor of these broader sub-concepts.

Important gaps exist in our understanding of spiritual coping for individuals with advanced heart failure. Rigorous intervention testing has not been conducted. Chaplaincy services have been the standard of care for some time but lack empirical support. Life review holds the potential to address the meaning and purpose domains of spiritual wellbeing but requires more rigorous testing before it is widely employed. There are some patient-generated interventions suggested in the literature, but these interventions have not been derived through methods that maintain congruence with the modern conceptual definition of spirituality.

The application of theoretical literature on spiritual coping to the problem in advanced heart failure has been inadequate. There is additional support for the stress-processing model in studies conducted in broader populations. Harris et al. (2013) utilized a qualitative methodology to assess the nature of meaning-based coping in community-dwelling elders, uncovering themes of God as a provider, relationship with God and social support of their faith community, and the experience of meaning (described in terms of purpose in life and a sense of worth or being needed). The inference is that older adults who are approaching the end of life shift their focus to meaning-based goals (Harris et al., 2013). The concept of meaning-making has also been proposed as a framework that nurses should use to address spiritual needs (Timmins et al., 2015; Timmins & Neill, 2013). Meaning-

making involves two domains: global and situational (Park & Folkman, 1997). Global meaning refers to a person's general orientation and understanding of many situations, whereas situational meaning relates to the immediate context (Park, 2013). Park (2013) asserts that the need for reevaluation of global and situational meaning occurs when there is a discrepancy between a person's current paradigm and situational circumstances. In this way, persons who are confronted with a distressing life situation reinterpret meaning to achieve personal growth and reconcile the discrepancy.

The theory of self-transcendence is also cited to explain why persons with terminal illnesses will seek meaning, purpose, and connectedness. The theory of self-transcendence was developed by Reed (1991) from a deductive reformulation of developmental theories. Reed (1991) suggested that adults continue to engage in developmental processes across the lifespan and that self-transcendence is a developmental process by which a person expands self-boundaries and shifts to a focus on life perspectives and broader purpose. This expansion of boundaries helps an individual to organize new information and challenges in a meaningful way, which leads to a sense of wellbeing and wholeness (Reed, 2018). This boundary expansion may happen intrapersonally, interpersonally, temporally, and transpersonally (Reed, 2018). The directions of expansion as further explained by Reed (2018) utilize ideas common to those themes expressed in qualitative literature on spirituality in heart failure. The theory of self-transcendence has been applied not only to older adults, but to situations in which persons are facing life-threatening experiences and terminal illnesses such as AIDS, breast cancer, and chronic illness (Reed, 2018). The theory of self-transcendence has not been specifically applied to the advanced heart failure population, but it might provide a beginning model for understanding spiritual coping in this population.

The stress process model and the theory of self-transcendence may also provide a framework for understanding how individuals can achieve spiritual wellbeing in the face of a terminal illness like advanced heart failure. One advantage of the theory of self-transcendence is that it is more congruent conceptually with spirituality. The stress process model is primarily focused on the creation of meaning within a stressful event, which fits with the sub-concept of meaning, purpose in spirituality but drops the sub-concept of connectedness (Folkman, 1997). Temporal boundary expansion in self-transcendence is defined as integrating one's past and future in a way that has meaning for the present, which also correlates to the sub-concept of meaning, purpose in spirituality (Reed, 2018). The advantage of self-transcendence is that it also includes interpersonal and transpersonal boundary expansion, which have to do with relationships with others, the environment, and "dimensions beyond the discernable world" (Reed, 2018). Thus, self-transcendence includes ideas related to both the sub-concept of meaning, purpose as well as connectedness in spirituality.

Literature Review Implications for Research and Practice

The concept of spirituality was historically synonymous with religion, but the literature has evolved in a way that separates the two concepts. As the body of literature on spirituality in advanced heart failure is considered, it is evident that conceptual ambiguity remains. The current literature points to a focus on life meaning, purpose, and connectedness, but does so inconsistently.

The quantitative literature focuses on correlations of spiritual wellbeing with several mental health and quality of life factors. Importantly, when spiritual wellbeing is measured using scales or subscales which operationalize meaning, purpose, and connectedness versus

religion, correlations with quality of life and depression remain intact apart from measures operationalizing religious aspects of spirituality. This lends support to the idea that the conceptual definition of spirituality should be separate from that of religion and that meaning, purpose, and connectedness are the most important defining characteristics. The quantitative evidence also confirms that spiritual needs and/or distress contribute to individuals' experiences of suffering.

The qualitative literature provides a body of descriptive evidence that focuses on describing the spiritual needs of individuals with advanced heart failure. The needs most often repeated are related to life meaning, purpose, and connectedness. Again, the expression of these ideas as the most common needs, suggests that the conceptual definition of spirituality should also be defined by these ideas. The frequency of meaning, purpose, and connectedness as expressed needs should direct clinicians toward finding interventions targeting these elements.

The literature presents unambiguous evidence describing spirituality in advanced heart failure but does not address interventions or spiritual coping mechanisms that may be used by individuals and clinicians to address spiritual needs. Currently available interventions or theoretical models for spiritual coping have not been tested in the heart failure population. The literature does not explain why particular persons experience lower spiritual well-being than others. We also do not understand how those with higher levels of spiritual wellbeing can achieve or maintain this in the context of living with heart failure.

To understand spiritual coping in advanced heart failure, research should focus on meaning, purpose, and connectedness as the most prominent concepts. Future research should focus on producing a more specific theory of spiritual coping in advanced heart

failure. Integrating the theory of self-transcendence, or the stress process model could be one approach. These theories both remain broad and lack specificity in describing spiritual coping within the experience of advanced heart failure. Additional theoretical work must be done to fill this gap in specificity. One way to do this would be to conduct studies aimed at understanding individuals' perspectives on whether and how they perceive themselves as vulnerable, and the strategies and skills they use to facilitate spiritual coping. A qualitative study should be completed examining if or how individuals perceive vulnerability in the context of advanced heart failure, how that perceived vulnerability affects their sense of meaning, purpose, and connectedness, and strategies they use to engage in spiritual coping to maintain spiritual wellbeing. Information from a qualitative study of this nature could lead to instrument development for perceived vulnerability in heart failure, construction of a spiritual coping in heart failure instrument, and design and testing of interventions to facilitate spiritual coping in advanced heart failure.

A systematic conceptual review of spiritual wellbeing instruments would bring improved clarity to existing research and improve the quality of future research. Further correlational research should be conducted reporting data for both meaning, purpose, and connectedness instruments and subscales, as well as data for religious, faith, and peace instruments and subscales. Research of this nature would refine the concept of spirituality, demonstrating its most impactful domains.

Focusing on meaning, purpose, and connectedness would help nurses to make a clear distinction between spirituality and religiosity. This clearer distinction may help practicing nurses to set aside discomfort in addressing spiritual needs. The North American Nursing Diagnosis Association (Anandarajah et al., 2016) has developed a diagnosis and definition of

spiritual distress (Herdman, 2009). Caldeira et al. (2013) proposed an updated definition, "A state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world or a Superior Being (p. 6)." This definition has a great degree of congruence with the consensus definition proposed by Puchalski et al. (2014) and again highlights the importance of meaning and connectedness.

Practicing nurses should focus on attending to the three sub-concepts of spirituality: meaning, purpose, and connectedness. Allowing individuals to reminisce may have benefits like life-review therapy but to a lesser intensity. Nurses should continue to engage in active listening and be both attentive to and present with the patient during care. Nursing presence may alleviate feelings of loneliness and engender a sense of human connection. Individuals who wish to engage in religious or spiritual rituals should be encouraged to do so. Though not rigorously tested, these spiritual interventions have been suggested in the nursing literature. The greatest force of this paper should be a reminder that the spiritual wellness of individuals in our care has a tremendous impact on their overall wellness. Attention to spiritual wellbeing should be a concern for nurses, equivalent to that of physical or emotional wellbeing.

Manuscript Two: Concept Analysis on Spiritual Coping in Terminal Illness and a Tentative Theoretical Framework

The meta-paradigm of nursing claims an interest in the promotion of health and wellness for individuals and communities using a holistic view (McEwen & Wills, 2014). This holistic view typically incorporates an understanding of the interaction between biophysical, mental-emotional, and spiritual domains, as these affect wellness for an individual or group (McEwen & Wills, 2014). Some theoretical models of coping include

aspects of spirituality as coping mechanisms to manage distressing situations (Folkman, 1997; Folkman & Lazarus, 1984; Reed, 2018). The concept of spiritual/religious coping has been used to identify and study spirituality as a coping mechanism (Folkman & Lazarus, 1984). Within the framework of nursing's holistic meta-paradigm, spiritual coping is an important concept worthy of definition, exploration, and for nursing, intervention. The concept of spiritual coping, however, is insufficiently differentiated from similar concepts of spirituality, religiousness, and religious coping with the terms often used interchangeably (Folkman, 1997; McSherry & Cash, 2004; Puchalski et al., 2014). In this concept analysis, I used a literature review to clarify the concept of spiritual coping by addressing two questions:

1. How is spiritual coping different from religious coping?
2. How is spiritual coping different from religious or spiritual participation?

Background

There is some empirical evidence that positive spiritual/religious coping can lead to improved mental health, resilience, and empowerment (Ai & Hall, 2011; Amjad & Bokharey, 2014; Hawthorne et al., 2017; Smith-MacDonald et al., 2017). Coping, as defined by Folkman and Lazarus (1984), is an individual's cognitive and behavioral effort to manage either internal or external demands that are interpreted as threatening or distressing. Spiritual/religious coping is one specific coping strategy among others, such as social support, problem-focused coping, or emotion-focused coping (Folkman, 1997). In the stress, appraisal, and coping model and subsequent work derived from it, spiritual and religious coping have often been represented as synonymous.

In clarifying the concept of spiritual coping, it would be helpful first to establish the distinction between the broader concepts of religion and spirituality. In literature before the

early 2000s, the concepts of spirituality and religiosity were often used interchangeably (McSherry & Cash, 2004). The religion-oriented view of spirituality stemmed from the dominance of a Judeo-Christian tradition in the Western academic context shared by many researchers and their subjects (McSherry & Cash, 2004). As the literature developed and diversified, a distinction became more visible. Now, researchers working in the realm of spiritual and religious belief and behavior tend to view spirituality as an umbrella term that incorporates the related concept of religion. Puchalski et al. (2014) used the Delphi method at an international consensus conference to develop this definition of spirituality:

> Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices. (p. 646)

Spirituality is conceptualized broadly and may incorporate beliefs or practices that lie within but also that exist outside any religious system. This more diverse and inclusive view of spirituality allows nurses to apply the concept of spirituality to all of humanity, even those who do not ascribe to a particular religion. In contrast, religion has been defined as a formalized system of beliefs, values, and practices (Blaber et al., 2015; Timmins & Neill, 2013). Religion provides some individuals with a framework or outlet in which to engage in spiritual exploration, expression, and spirituality (Naghi et al., 2012) but is not necessary to those activities. The distinction between spirituality and religion suggests that spiritual coping and religious coping may also be distinct concepts. This analysis tests that supposition.

Concept Analysis Methods

I adapted Walker and Avant's (2011) concept analysis method, which included seven steps: select a concept; determine the purpose of analysis; identify all uses of the concept; define attributes; identify a model case; identify borderline, related, contrary, invented, and illegitimate cases; identify antecedents and consequences; and define empirical references (Walker & Avant, 2011). Walker and Avant's approach aims to identify an underlying or essential conceptual definition that can then guide theory and research development. The use of cases in the method serves to illustrate the concept and call into relief how the concept differs from similar concepts. I endeavored to avoid one weakness of Walker and Avant's (2011) method, one common to many concept analyses approaches, an inadequate account of how defining attributes of a concept are identified (Paley, 1996). I used a broad literature search to identify uses of the concept, then submitted the text of retained articles to thematic analysis using the procedure outlined by Nowell et al (2017). By applying a formalized thematic analysis process to the literature and thereby inductively deriving a conceptual definition, I more clearly laid out an account of how defining attributes of the concept were defined. The literature search provided further opportunities to identify a range of antecedents, consequences, and empirical referents of the concept.

To identify uses of the concept, I conducted a comprehensive literature search on *spiritual coping* as a mapped term and as a keyword in the CINAHL, PubMed, PsychInfo, PsychArticles, and Medline databases. Inclusion criteria included English language, published 2007-2018, and spiritual coping as the central concept or measure. Dissertations, theses, or anecdotal narratives were excluded. While many sources used the term spiritual coping, often those mentions occurred only in a conclusion section as a broad explanation of

the results. The searches rendered 869 citations. I then reviewed the abstracts for inclusion and exclusion criteria and removed duplicates, leaving 187 citations. These citations were subjected to a full-text review for inclusion and exclusion criteria, leaving 135 citations included in the review. Pargament (2003) was added to this list, as it is the original psychometric work for the spiritual coping instrument used in many of the quantitative studies.

Each of the retained full-text citations was treated as a unit of data and subjected to a thematic analysis. Language about spiritual coping used in the background, theoretical framework, and discussion sections were of particular interest in the analysis. There were also several psychometric articles evaluating measures of spiritual coping. Those psychometric articles that included factor analysis were particularly helpful sources of data.

I employed the thematic analysis method explicated by Nowell et al. (2017) in which the first phase is to familiarize oneself with the data. I did this by engaging in an initial reading of the texts to gain a sense of the whole body of data. Phase 1 occurred during my initial full-text review looking for inclusion and exclusion criteria. Notes were kept during Phase 1 to serve as a reference to the gestalt of this large body of literature. Phase 2 involved the generation of initial codes, which I did upon a second, closer reading of the retained texts. My initial aim was to include all 135 citations in the coding and analysis, but I began to notice a pattern of data saturation after 35 citations, meaning codes began to repeat with no new codes emerging. At this point, no further articles were submitted to thematic analysis. Again, Pargament (2003) was intentionally retained because of its original psychometric work, including factor analysis, to operationalize spiritual coping. Found in Appendix A is a basic chart of the citations retained for subsequent analysis. This smaller body of literature

includes a diversity of quantitative and qualitative work, done in a variety of environments, and focusing on various problems for which spiritual coping might be utilized.

Each text was coded separately and organized in an Excel spreadsheet that would later allow me to sort the data fields according to the codes. Sorting the data fields occurred during Phase 3, in which these initial codes were used in an iterative process with the raw textual data to search for broader themes. Phase 4 of the analysis involved a review of the themes to look for a coherent pattern of meaning (Nowell et al., 2017). I also returned to notes from Phase 1 to ensure that the main thrust of the larger body of literature was not lost. Phase 4 led me to develop a pictorial model of the spiritual coping concept (Figure 1) and to clarify defining attributes, antecedents, and consequences.

Results

Antecedents

Antecedents are those things that must occur for an instance of the concept of interest to occur (Walker & Avant, 2011). In the case of spiritual coping, antecedents would include a *personally meaningful spiritual framework* and *stressor*. Spiritual coping must be preceded by some kind of a meaningful spiritual framework. Such a framework is not developed amid a crisis, but it is present before the need to draw on it for coping strategies (Ai & Hall, 2011). As researchers have discovered, religiousness alone did not predict positive coping outcomes, but religiousness tied to *spiritual connection* or, "a deep connection with a higher power or a spiritual relationship in faith (Ai & Hall, 2011, p. 2)," did correlate with positive outcomes. Therefore, positive strategies employed as coping mechanisms grow out of a personal belief or spiritual connection that is integrated into the life paradigm of the individual (Ai & Hall, 2011). By contrast, merely adhering to a religious system does not

constitute a personally meaningful spiritual framework (Ai & Hall, 2011). Ai and Hall (2011) recognized that for spiritual/religious coping to be effective in a positive sense, there must be an essential spiritual connection between beliefs and actions. Charzynska (2015) provided additional evidence that religious practice as a way of coping without the associated personal meaning, such as religious attendance or religious community activities done habitually without real connection, have little effect on coping outcomes. Writers in the studies I reviewed indicated that observance of religious or spiritual activities outside of a personally meaningful spiritual framework rarely resulted in coping benefits.

Life stressors. As a domain of Folkman and Lazarus's (1984) theory of coping, spiritual coping is always aimed at responding to a stressful situation, so *life stressor* was included as an antecedent of spiritual coping. Folkman and Lazarus (1984), in the stress, appraisal, and coping model, posit that a stressful event initiates an appraisal process in which a person evaluates the event and their available resources for responding to that event. After this appraisal, the person engages in coping strategies aimed at resolving the stress. Without a stressor coping does not occur since it is unnecessary.

Further, a distinction between spirituality and spiritual coping was not explicitly clear in the literature but was implied or assumed. Spirituality can exist for individuals outside of a coping response to a threat. If we think of spirituality as an intrinsic aspect of humanity, then it would have to exist even without a life stressor (Puchalski et al., 2014). Therefore, spiritual coping exists in response to a life stressor, but spirituality can exist even without such a stressor.

Defining Attributes

Through the four-phase thematic analysis, the inductively derived defining attributes of spiritual coping were 1) *cognitive efforts derived from a personally meaningful spiritual framework* 2) *behavioral efforts derived from a personally meaningful spiritual framework*. The resulting definition of spiritual coping is: cognitive and behavioral efforts derived from a personally meaningful spiritual framework employed in response to life stressors.

Cognitive and behavioral efforts. The cognitive and behavioral efforts of spiritual coping refer to specific thought processes, beliefs, or actions employed by the individual in response to distressing stimuli. These cognitive and behavioral expressions of spiritual coping have long been understood to include both positive and negative dimensions (Ai & Hall, 2011; Allen et al., 2013; Vitorino et al., 2017). The positive and negative dimensions found in the literature reflect the consequences of the coping efforts. That is, positive spiritual coping is positive because it leads to a positive response to the stressor, one that helps the individual achieve wellbeing. Negative spiritual coping is negative because it leads to a negative response to the stressor, usually one that results in poorer wellbeing. Such a dynamic may oversimplify the relationship between a strategy and the valence of its result, leaving out the possibility, for instance, that any given strategy could be ineffectively exerted and lead to a converse result. For example, ineffective positive spiritual coping might lead to negative consequences. One might also conceptualize positive as active (specifically making changes) and negative as passive (specifically avoiding changes), but this framework was not identified in the literature. Spiritual coping strategies identified in the literature that generally led to positive outcomes included: reaching out to the transcendent; searching for meaning, significance, or control; drawing on inner strength; and framing or reframing stressful events.

Spiritual coping strategies that lead to negative outcomes included questioning the transcendent, anger towards a higher power, and framing an event as punishment.

It is also important to note that spiritual coping may involve religious coping, but this is not a necessary condition. The conceptual independence of spiritual and religious coping was supported in the psychometric work of Charzyńska (2015), in which religious coping and spiritual coping were operationalized discretely, with spiritual coping emerging as a stronger predictor of theorized outcomes. Though the terms spiritual coping and religious coping have been used interchangeably and even combined (spiritual/religious coping) they should be viewed as conceptually distinct (Folkman, 1997; Folkman & Lazarus, 1984; McSherry & Cash, 2004). Religious coping is one form of spiritual coping that is structured around the narrower concept of religion rather than the broader concept of spirituality. Those engaging in spiritual coping may employ, either positively or negatively, religious coping strategies. Religious coping strategies identified in the literature include payer, reading of sacred text, worship, religious group association, religious rites, and particular religious beliefs.

Cases

Walker and Avant (2011) advocate the use of cases to clearly show an instance of the concept and to delineate the concept of interest from phenomena that may be borderline or related. I used a model case to show a complete instance of spiritual coping and to demonstrate that religious coping can be included within spiritual coping. A borderline case was used to demonstrate the necessity of a *meaningful spiritual framework* within spiritual coping. Two related cases were used to differentiate spiritual coping from spirituality and general coping. A brief analysis will accompany each of the cases.

Model Case. Marla is a 37-year-old woman who lives in a rural area of the United States with her husband and two children. She considers her faith an integral part of her life in that she has expressed a personal commitment to the beliefs and practices of her congregation. Marla engages in regular personal prayer and worship as well as church attendance and devotes time to serving the older members of her congregation (*personally meaningful spiritual framework*). Marla has been hospitalized due to severe anemia, cardiogenic shock, and subsequent heart failure (*life stressor*). In response to this diagnosis and the treatment that followed, Marla has engaged in prayer, meditation, and reading her Bible (*behavioral efforts derived from a personally meaningful spiritual framework in response to a life stressor*). Marla has also communicated that her faith has helped her to see her suffering as a way to grow closer to God (*cognitive efforts derived from a personally meaningful spiritual framework*). Marla does not recover fully from her health problems but feels a sense of peace and acceptance regardless.

Borderline Case: Religious Practice Without a Personally Meaningful Spiritual Framework. Marla is a 37-year-old woman who lives in a rural area of the United States with her husband and two children. She sometimes attends church in observance of family traditions. She personally does not feel that church or her faith is especially important to her. Marla has been hospitalized due to severe anemia, cardiogenic shock, and subsequent heart failure (*life stressor*). In response to this diagnosis and the treatment to follow, Marla has allowed the chaplain to pray over her because it is important to her husband that this happens (*behavioral effort in response to a life stressor but not derived from a personally meaningful spiritual framework*). Marla does not recover fully from her health problems and has suffered from depression and episodes of explosive anger. Marla has attempted to use religious coping

strategies but does not assign personal meaning to the strategy employed.

Related Case: Spirituality. Marla is a 37-year-old woman who lives in a rural area of the United States with her husband and two children. She considers her faith an integral part of her life in that she has expressed a personal commitment to the beliefs and practices of her congregation. Marla engages in regular personal prayer and worship as well as church attendance and devotes time to serving the elderly members of her congregation (*personally meaningful spiritual framework*). Marla enjoys a sense of meaning, peace, and connectedness in her life. (*Absent life stressor, absent behavioral or cognitive response.*)

Related Case: Coping. Marla is a 37-year-old woman who lives in a rural area of the United States with her husband and two children. Marla has been hospitalized due to severe anemia, cardiogenic shock, and subsequent heart failure (*life stressor*). In response to this diagnosis and the treatment to follow, Marla has relied heavily on her social support network, including her husband. She also tried to focus on solving problems as they arise and often repeats the mantra "control the controllable" (*cognitive and behavioral efforts to respond to a life stressor*). Marla does not fully recover from her illness but has adjusted to her new normal, living a satisfying life. (*Absent personally meaningful spiritual framework.*)

Consequences, and Empirical Referents

Spiritual coping is a broad concept with far-reaching consequences. The literature yielded several adaptive and maladaptive consequences that may follow spiritual coping. These are visually represented in Figure 1. Adaptive consequences are adaptation to stressors or suffering (Park et al., 2017; Romeiro et al., 2017; Vitorino et al., 2017); acceptance of change or the reality of death (Mangolian Shahrbabaki et al., 2017; Saarelainen, 2017; Simonic & Klobucar, 2017); spiritual growth (Ai & Hall, 2011; Allen et al., 2013;

Saarelainen, 2017; Van Tongeren et al., 2017); improved mental health (Ai & Hall, 2011; Allen et al., 2013; Vitorino et al., 2017); increased resilience (Amjad & Bokharey, 2014); maintenance or improvement of spiritual wellbeing (Amjad & Bokharey, 2014); maintenance or improvement of quality of life (Cruz et al., 2017; Matos et al., 2017). Maladaptive consequences are the converse of those listed for positive consequences.

Empirical referents are those things that demonstrate, usually in measurable terms, the occurrence of the concept (Walker & Avant, 2011). Empirical referents for spiritual coping would be studies or instruments that collected data on spiritually related beliefs and/or behaviors employed in addressing a stressful situation. Examples of positive and negative spiritual coping beliefs and/or behaviors are found in the conceptual model (Figure 1). Some examples of cognitive and behavioral efforts used in spiritual coping with their references from this analysis include: reaching out to the transcendent (Adams & Roberts, 2010; Ai & Hall, 2011; Cabaco et al., 2017; Saarelainen, 2017); searching for meaning, significance, or control (Ai & Hall, 2011; Hawthorne et al., 2017; Pargament, 2003; Saarelainen, 2017; Simonic & Klobucar, 2017); drawing on inner strength (Mangolian Shahrbabaki et al., 2017; Saarelainen, 2017); and framing/reframing stressful events (Pargament, 2003; Simonic & Klobucar, 2017). Some examples of negative spiritual coping strategies with their references include questioning the transcendent (Ai & Hall, 2011; Allen et al., 2013); anger towards a higher power (Ai & Hall, 2011); and framing events as punishment (Park et al., 2017). Religious coping strategies, such as reading texts, prayer, or ritual attendance may also be empirical referents of spiritual coping, but only in specific cultural/religious contexts.

Discussion and Implications

This concept analysis aimed to clarify the concept of spiritual coping by

distinguishing it from general spiritual and/or religious practice on the one hand and religious coping on the other. Foundationally, spirituality and religion/religiosity are different concepts. This suggests, and the literature supports the conclusion, that spiritual coping and religious coping are also different concepts. Spiritual coping may be viewed as a broader term that can incorporate religious coping. Spiritual coping is also a distinct concept from spiritual and/or religious practice. Practices can and do occur outside of the need to address a particular problem or threat. Using the parent concept of coping, spiritual coping occurs only in response to a stressor, problem, or threat. For nursing, the benefit of focusing on spiritual rather than religious coping is that spiritual coping encompasses those who do not claim a religious orientation. Clarifying the concept of spiritual coping allows nursing scholars and practitioners to realize the holistic view of people and wellness that they have claimed in their paradigm.

CHAPTER 3

METHOD

In this narrative inquiry study, I used open-ended interviews to explore narratives of spiritual coping among patients with terminal heart failure. I analyzed the narratives for the explicit and implicit meanings that participants assigned to their experiences and identified patterns across interviews. I began with the assumption that the meaning developed in the narratives was a kind of personal theory about spiritual coping during terminal heart failure in accordance with Riley and Hawe (2004). I extracted these personal theories from multiple cases, which rendered three plot patterns. These plots were synthesized into a theoretical model of spiritual coping in terminal heart failure meant to guide nursing practice and serve as a foundation for developing nurse-led spiritual interventions.

Sample and Setting

The target population of this study was patients with terminal heart failure. Potential research participants were recruited using the following inclusion and exclusion criteria. Inclusion criteria were a diagnosis of heart failure class III-IV (New York Heart Association functional classification) as indicated in the medical record, ability to understand and speak English, ability to complete a one to two-hour interview, and ability to satisfactorily and independently complete the consent process. Exclusion criteria are memory or cognitive impairment indicated by a score of less than 25 on the Mini-Mental Status Examination (Mitchell, 2009) and significant comorbidities such as cancer or other terminal diseases.

Setting for Recruitment

I recruited participants from the inpatient cardiovascular units, including the general floor and intensive care units at the University of Missouri Hospital in Columbia, Missouri.

This is an academic, tertiary, Level 1 trauma center with 247 beds (Curators of the University of Missouri, 2019). The inpatient cardiovascular units have approximately 47 beds, which include intensive care, cardiac progressive care, and medical-surgical beds. This hospital serves patients from broadly diverse geographic, ethnic, and sociocultural backgrounds, most of which reside in counties in central Missouri. This region primarily includes rural settings but also several moderate-sized cities. The University of Missouri is in Columbia, MO, drawing a culturally and ethnically diverse population. An estimated 15-20 patients per month are treated in the inpatient cardiovascular service line units. Support letters from the institutions detailing access to potential participants are available in the appendices.

Recruitment Plan and Sampling Procedures

I selected cases purposively based on the participant's heart failure stage, age, and spiritual or religious background based on information in the medical record obtained after the participant had signed the HIPAA authorization form. In my study, purposive sampling was appropriate since I sought to explore individual perspectives of spiritual coping and use these perspectives to develop a theoretical framework. A rich description of spiritual coping used to build such a framework should include a diversity of participant backgrounds and contexts because spirituality is an experience that interacts with many aspects of culture (Puchalski et al., 2014).

Sample sizes in qualitative research are commonly based on the aim of achieving saturation. Saturation is a concept that has multiple meanings and limited transparency since there is no way objectively to prove that all meanings are accounted for, that if one more case were sampled no added information would be forthcoming (O'Reilly & Parker, 2012). In grounded theory, theoretical saturation is the point at which no further cases are needed

because the categories in the emergent theory appear to be developed fully and distinctions between them explained (O'Reilly & Parker, 2012). In thematic or content analysis, data saturation describes the point at which no added information is likely to come from additional cases (O'Reilly & Parker, 2012). During the initial case analysis that occurred as recruitment progressed, I monitored for both theoretical and thematic saturation since my study aim addresses both. Individual narrative saturation occurred as participants began to repeat themes near the end of the interview. I used the conceptual model to make a determination of saturation in the kinds of cases represented by the interview by including stories in the sample with both positive and negative spiritual wellbeing outcomes.

Estimating the necessary sample size in qualitative research can be quite difficult, but the richer and thicker the qualitative data, the smaller the sample size required (Finfgeld-Connett, 2018a). In circumstances with rich data, as in the proposed narrative analysis, samples as small as six cases are adequate (Finfgeld-Connett, 2018a). Based on Finfgeld-Connett's assertion, I estimated the necessary sample size at less than 10 participants.

To recruit patients for the study, I asked a cardiovascular unit supervisor (CVUS), a heart failure nurse care coordinator (HFNCC) to screen the daily patient list for potential participants according to the inclusion and exclusion criteria. The cardiovascular unit manager agreed to this procedure (Appendix B). In the initial plan, the CVUS or HFNCC were asked to approach prospective participants while they were in the hospital to determine the patient's interest in participating in the study. The HFNCC requested that interested patients sign the HIPPA authorization and then contacted me daily with a list of potential participants who expressed interest.

Emergent Changes in Sampling

The COVID-19 pandemic, which began shortly after recruitment began in March 2020, created barriers to sampling in the hospital setting due to limited patient access. In June 2020, I submitted an IRB amendment to obtain intuitional review board approval to recruit through several heart failure support groups on Facebook. This effort involved posting recruitment materials in private groups with the permission of the group administrators. Notices in the groups advised individuals to private message me or contact me at my professional email account for more information. I posted Facebook notices during June and July 2020.

Data Collection

This study aimed to explore narrative accounts of spiritual coping in terminal heart failure. Data collected included demographic information, data from one-on-one interviews, and field note observations. The data collection process began after participants signed the informed consent.

Procedures

When I was alerted that a prospective participant had been identified by the HFNCC, I went to the unit to screen that person for eligibility, describe the study, and obtain consent. Demographic data were collected from each patient for later use in describing the sample. The demographic data collection tool is located in Appendix C and includes age, gender, religious preference, heart failure stage, marital status, medical/psychiatric diagnoses, and ethnicity.

After completing the demographic survey with each patient, I scheduled an interview after the participant's expected date of discharge from the hospital. The setting for the in-

person interviews was the participant's home or a public place selected by the participant. Following Gubrium and Holstein's (2009) contextualized approach to narrative inquiry, I chose to interview participants in their own homes or chosen spaces, because that would allow for observation, including some access to the culture and context of their day-to-day surroundings.

The COVID-19 pandemic made it impossible to interview some participants in their place of residence. Those who were being discharged to a restorative care environment such as a nursing home or rehabilitation center were under strict quarantine and had limitations on visitors. Therefore, some participants were interviewed in their hospital rooms. Efforts were made to diminish interruptions by coordinating the interview time with the nursing staff during periods when few nursing care interventions were scheduled. Using this strategy, interviews did not suffer from substantive interruptions.

Initially, a second round of interviews was planned, but these follow-up interviews were determined to be unnecessary. The number of interviews was not specified in the original IRB submission, so an amendment was not submitted. The initial interviews were detailed and robust, with most participants repeating narrative content near the ends of their interviews. I interpreted this to mean that the participants had shared all that they wished to share about their experience, rendering a second interview an unnecessary burden to them. Other changes made to the sampling and data collection procedures because of COVID-19 are detailed in Appendix D.

Interviews

The narrative interview with each patient followed an unstructured format. Narrative interviews do not follow a structured interview guide but tend to pose one or two broad open-

ended questions in a conversational format (Gubrium & Holstein, 2009; Jovchelovitch & Bauer, 2000; Riessman, 2008). The interview guide begins with a simple definition of spirituality: “Some people have defined spirituality as a combination of finding meaning and purpose in life and feeling connected to something. What does spirituality mean to you?” I followed this defining and orienting question with the primary life narrative question: “Tell me the story of your spiritual life since you first learned you had heart failure to the present.” I posed follow-up questions as needed. These included prompts such as, “Then what happened?” and “Some people say that things change after they become sicker, others say it does not make much difference. What about you?” Additional prompts appear in the full interview guide along with questions that were to be posed in second interviews (Appendix E). All interviews were audio-recorded, contingent on participant consent, with recordings deleted from the recording device after being uploaded to REDCap storage on the secure University of Missouri-Kansas City server. A bonded, professional service was used to transcribe all recordings. To preserve the participant's voice, transcription was verbatim, including linguistic and para-verbal elements of delivery, such as pauses, false starts, and other non-linguistic utterances (Riessman, 2008). I compared each recording with the resulting transcript to verify the accuracy, editing the data for clarity while again attempting to preserve a sense of the participants’ linguistics.

Observations

In addition to audio-recorded interview data, observational field notes were collected during each interview. Field notes were recorded in an unstructured format but addressed when and where the interview occurred and commentary on the non-verbal and para-verbal communication techniques the participant used throughout the interview. An attempt was

made to jot a word or phrase that could later be used to associate the body language notation with a timestamp in the interview (Montgomery & Bailey, 2007). Non-verbal and para-verbal communication can include body position, eye contact, and gestures. It is especially important to note these features at transition points in the narrative or critical plot points (Riessman, 2008). Third, I wrote reflective commentary on the major points of the narrative and initial impressions. This commentary also included reflective analytical notes with tentative theoretical propositions or themes (Montgomery & Bailey, 2007).

I estimated that the narrative interviews would take about one hour each, with the originally planned second interviews and confirmatory checking interviews taking no more than one additional hour. I anticipated that attrition could be a problem as it often is in palliative care research (Preston et al., 2013). To enhance retention, I provided a small gift card incentive upon completion of the interview, and strict adherence to eligibility criteria were used during recruitment to improve the likelihood that participants would physically and cognitively be able to complete the study (Jordhoy et al., 1999). Five participants who consented to participate were not interviewed. Three had a serious decline in physical condition and died before being interviewed. Two did not keep their interview appointments and were lost to follow-up.

Human Subjects Protections

This project was approved as exempt by the Institutional Review Board (IRB) at the University of Missouri – Kansas City (UMKC; No. 19-109). I completed CITI Program Human Research – Group 1 Biomedical Investigator training as required. The study involved minimal risks to human subject participants, namely a possibility of being fatigued by the interview or experiencing emotional discomfort from the personal nature of the interview

questions. These risks were minimized by interviewing participants in the comfortable environment of their choice. Each participant, via their association with the University of Missouri Health System, also had access to outpatient psychological services or a social worker. I gained permission to refer participants to these services if signs of distress arose, including evading questions, closed body language and para-verbal communication, or physical signs of anxiety and stress. I received specific training on narrative interview techniques in one-on-one course work with an experienced narrative researcher. In addition, I am a practicing mental health nurse with experience in therapeutic communication and psycho-emotional assessment.

There were potential individual benefits to participation. In previously published interview studies with participants at the end of life, interviewees experienced positive psychological benefits from the opportunity to tell their stories or express feelings (Chen et al., 2017). Benefits to society and health knowledge included a deeper understanding of spiritual coping processes that may lead to future interventions aimed at facilitating spiritual coping and relieving spiritual distress in patients in the end-of-life stage. Interviewees also received $25 gift cards as a thank you for their time and participation.

Protected health information, interview transcript data, and participant confidentiality are secured in the University of Missouri – Kansas City encrypted electronic data management storage. Interview recordings were uploaded immediately to REDCap on the secure University of Missouri – Kansas City encrypted storage server and deleted from the recording device. Field observational notes and demographic data were entered directly into RedCap.

Data Analysis

Interview transcripts were the primary data source for analysis. However, Gubrium and Holstein (2009) argue that simple textual analysis, or the collection and summarization of major themes, is not sufficient for understanding the true nature and meaning of narratives. Therefore, ethnographic-style field notes (Emerson et al., 2011) were incorporated to develop a holistic picture of spiritual coping in end-stage heart failure. Utilizing interview transcripts and field notes, I analyzed individual narratives first using thematic and structural techniques based on Riessman's (2008) descriptions. Then I compared conclusions from individual narratives to synthesize themes and structures into a theoretical framework of spiritual coping in heart failure. To facilitate data management, I uploaded interview transcripts and constructed analytic memos within Dedoose, a password-protected qualitative analysis application (Dedoose Version 8.0.35, 2018).

Individual Narrative Analysis

In the first layer of analysis, I utilized thematic and structural analysis techniques based on Riessman's (2008) descriptions. Thematic analysis is an approach focused on identifying repeated patterns in interview content (Riessman, 2008). The narrative of each participant is left intact, and themes are identified within the narrative first (Riessman, 2008). Then, holistic themes and meanings are compared between cases to move toward more generalizable research conclusions. Structural analysis focuses attention less on the content and more on how the story is told (Riessman, 2008). Structural analysis attends to components like genre, plot, sequencing, and contours of the story (Riessman, 2008). Structural analysis, by nature, requires that the narrative remain intact, and a holistic approach be used to identify plot structures in single narratives first. Multiple narratives were

then compared for similarities in plot structure to identify if there were common plots among those who lived through the experience of heart failure.

In the first phase of analysis, I read the entire interview transcript to get a sense of the narrative whole. Then I completed additional readings, looking for repeated meanings and patterns in individual narratives with regard to thematic content and structure. In the second phase, I sectioned out important passages in the data and attached analytic commentary to them. I added annotations to track structural elements such as characters, plot structure, themes, and explicit meanings conveyed by the narrator. Annotating directly on the transcript allowed me to track the defined elements without separating them from the context of the entire narrative. I also linked elements from my field notes to segments of the narrative to add depth and data triangulation to the analysis process. These analysis memos allowed me to remain anchored in the interviews while also beginning to synthesize meanings into the theoretical concepts, relationships, and sequences (plots) that eventually formed my central finding, a framework of spiritual coping. In the final phase of analysis, I took the analysis memo conclusions and returned to the narrative text to ensure that the interpretations maintained fidelity and connection to the whole narrative. Corrections or additional analytic memos were constructed based on this comparison.

A second reader, an advisor experienced in narrative methods, engaged in the same procedure for the first two narrative transcripts to verify meanings and themes. Analysis memos for individual studies, mine as well as those of the second reader, were compared and discrepancies discussed, leading to a synthesized analysis memo that reflects mutually derived meanings and themes. I completed narrative analysis alone, following the same steps for the remaining transcripts.

Across-Case Synthesis, and Theoretical Model Generation

The goal of the synthesis in this dissertation was to generate a theoretical model to explain how persons who have terminal heart failure developed spiritual coping. After the individual narratives were analyzed using the preceding steps, the conclusions from each were compared across cases. Each analyzed narrative was treated as a stand-alone case study on spiritual coping in heart failure, representing an individual's theory about the phenomenon. The initial focus of the synthesis was to group narratives according to similar structural patterns or plots. These plot sequences provided a structure in which thematic content from narratives was grouped into categories that formed the basis for theoretical concepts.

Diagramming also provided opportunities for constructing dynamic relationships between the developing categories and concepts. To keep the theoretical model construction linked to the foundational text, I engaged in an iterative process in which I returned to whole narrative transcripts to verify interpretations and confirm that connections were maintained between the developing theoretical model and the texts of the narratives. In this way, the holistic nature of the narrative inquiry was preserved, while at the same time allowing for higher-level abstraction and theoretical model construction. A higher-level abstraction of this nature is essential if the theoretical model is to be generalizable enough to guide research and practice (Finfgeld-Connett, 2018b). This synthesis resulted in a process diagram and descriptive theoretical model that was directly based on the experiential context of patients with terminal heart failure.

Rigor

An explosion of interpretive methods was unleashed during the mid-twentieth century, when postmodern ways of viewing history, art, and science began to challenge, in earnest, the established master narratives of modernism and the assumptions of naïve realism (Denzin & Lincoln, 2018). The new naturalistic paradigm that emerged (Lincoln & Guba, 1990) has created significant problems for social scientists who seek to establish standards for rigor in qualitative research. Rigor refers to the quality of carefulness, exactness, thoroughness, and accurateness in the research design, sampling, data collection, analysis, and interpretation (Cypress, 2017). Rigor often gets distilled to the concepts of reliability and validity (Davies & Dodd, 2002). Validity, in a quantitative study, refers to the degree to which a study measures what it purports to measure and can be trusted to yield conclusions that are generalizable to other persons or settings (Noble & Smith, 2015). Some argue that this form of validity cannot be appropriately applied to interpretive research, where the "reality" being assessed might mean someone's belief, fear, self-identification, prejudice, fantasies, or other intangibles (Noble & Smith, 2015; Whittemore et al., 2001). The broad-brush application of validity criteria is problematic because qualitative approaches are vastly different in focus and method (Whittemore et al., 2001). Instead, Guba and Lincoln (1985), and many who followed them, have proposed diverse alternative criteria to establish a study's rigor—qualities like credibility, confirmability, authenticity, and transferability (Denzin & Lincoln, 2018)—and proposed a variety of strategies to meet them. Still, others argue if validity is at base the extent to which a study's findings truthfully represent some reality about the world, *any* approach claiming to be science must concern itself with questions of validity (Davies & Dodd, 2002; Patton, 2015). What all agree on is that

whatever name it goes by, the issue of truth and the credibility of its claims commands our attention because we must convince readers of the trustworthiness of our data and interpretations (Riessman, 2008).

In this study, I adopted Riessman's (2008) bipartite account of validity, which has the advantages of striking a middle position *and* focusing specifically on narrative inquiry. First, Riessman distinguished two levels of validity: the validity (i.e., correspondence with reality or truth) of the story told by the participant and the validity of the analysis or story told by the researcher. The importance of each of these levels can depend on the study's aim. If studies aim to present a historical retelling of events or simply publish participant stories, it becomes critically important to validate the story told by the participant. If a study aims to take participant narratives, subject them to analysis, and then draw out meanings or conclusions, the validity of the story told by the researcher about the narratives becomes more important. Riessman further suggested that validity of either type could be evaluated in narrative inquiry research through evidence of correspondence, coherence, persuasiveness, pragmatic use, political use, and ethics. Riessman clarified that not every aspect of validity was relevant in every study. The principles are a guide that can be calibrated to the aim and methods of the research and the epistemology and goals of the research/researcher.

Each of Riessman's (2008) principles were applied in this study. First, correspondence refers to validity on both levels, the validity of the story told by the narrator and the validity of the story told by the researcher. Regarding the first level, one might ask, "Does the narrator's story correspond to the objective facts of the case or the historical evidence?" In this study, my inquiry is only minimally concerned with the historical accuracy or objective truth of the events reported by participants, so this criterion does not apply. What

is more, at stake is how the participants represented their realities and the meanings they ascribed to them. The second sense in which correspondence must be addressed has more applicability: the validity of the interpretation (or the degree to which the interpretation corresponds with the evidence). Correspondence, in this regard, can be established by providing a reader with evidence of a connection between narrative content and the interpretation. I will do this by sufficient sampling of the interview data and clear accounts of where and how data and findings in the form of an audit trail of transcription and analytical processes (Riessman, 2008). Audit trail material, in this study, includes interview recordings, transcriptions, field notes, and analytical and/or reflexive memos. Moreover, this design provides additional validation that interpretations correspond to the narratives through checks with the second reader (advisor) as an expert in the content area.

Coherence is a criterion that examines whether elements of a narrative story fit together and whether theoretical or interpretive arguments fit together logically. In this study, the aim is to include enough transcript data to allow readers to determine if the interpretive results maintain coherence. Coherence was also enhanced through a comparative analysis between narratives and triangulation of varied data collection methods, which include both interview and observational data (Riessman, 2008).

Persuasiveness is the idea that the theoretical claims made are supported by evidence from direct accounts and that the researcher has adequately addressed negative or alternative interpretations (Riessman, 2008). Again, this criterion is satisfied by providing narrative textual evidence to support theoretical claims. The theoretical claims made in this study are evaluated for logical coherence through theoretical generalizability and logical congruence with existing theory or logical challenges to existing theory (Finfgeld-Connett, 2018b).

Pragmatic use examines whether the research becomes the basis for others' work. It is too early to tell whether this study will meet this criterion, as it is usually assessed based on the number of citations of the work that appear in other peer-reviewed publications (Riessman, 2008). The same might be said of political and ethical use. These criteria examine how the research helps those who were part of the research (Riessman, 2008). Will this research effect change in the health system to improve or promote spiritual coping in patients with heart failure? Will the participants in the study benefit directly from their involvement? The answers to these questions are beyond the scope of this dissertation. In this study, I aimed to meet three of Riessman's validity criteria for narrative inquiry, including correspondence, coherence, and persuasiveness. In that way, I established the rigor of the research and its potential for application in practice and as a guide for further research.

Conclusion

My aim in this study was to collect narratives of spiritual coping in terminal heart failure and synthesize these into a theoretical framework. I recruited participants from the cardiology unit and cardiac ICU of a Midwestern, Level 3, academic health center and through private heart failure support groups on social media. Participants were diagnosed with stage III or IV heart failure but varied in age, religious background, and heart failure stage. I used narrative inquiry techniques primarily based on methods described by Riessman (2008) and Jovchelovitch and Bauer (2000). Open-ended interviews elicited narratives of spiritual coping among patients with terminal heart failure, which I analyzed as single cases thematically and structurally. Next, I categorized cases according to structural plots and used cross-case comparisons within those categories to build theoretical concepts. These were all

synthesized into a model of spiritual coping in terminal heart failure aimed at supporting spiritual care in practice and future research.

CHAPTER 4

RESULTS

Manuscript: A Theory of Spiritual Coping in Terminal Heart Failure Developed Through Narrative Inquiry

Heart failure is a complex medical problem that includes elements of acute, chronic, and terminal illness (Mann et al., 2018). Those in the late stages of heart failure experience substantial personal suffering in physiological, psychological, social, and spiritual domains (Kavalieratos et al., 2017). The complexity of the disease process and suffering experience results in significant health care costs, estimated to be $160 billion by 2030 (Heidenreich et al., 2013), and personal burden. Those in terminal stage heart failure can benefit from palliative care, which can alleviate suffering and reduce health care costs (May et al., 2014; Smith et al, 2014). Palliative care implements a uniquely holistic approach among medical specialties, including attention to spirituality, making it a logical practice area in which to address spiritual suffering (Braun et al., 2016). However, the current literature on palliative care for patients with terminal heart failure provides a poor theoretical basis for interventions to promote spiritual wellness.

What is missing is a theory to describe the particular spiritual coping processes that patients follow in seeking to meet their spiritual needs in the unique context of terminal heart failure. Some theories have been used to describe or explain spirituality and coping in other chronic and terminal illnesses, but not heart failure (Folkman & Lazarus, 1984; Steinhauser et al., 2008; Tiew et al., 2013). There are also several adequate descriptions of patients' perceived spiritual needs in terminal heart failure (Murray et al., 2004; Murray et al., 2007; Ross & Austin, 2015), but there is much less in the literature to show how patients with

terminal heart failure perform and experience spiritual coping (Clark & Hunter, 2019). This gap is significant because we have evidence that patients with terminal heart failure experience spiritual wellbeing in unique ways compared to patients with other diseases.

Spiritual wellbeing for patients with heart failure mirrors the physical pattern of decline in heart failure, the slight improvements and then further declines repeating in an overall declining, cyclical nature (Murray et al., 2007). In cancer, by comparison, spiritual wellbeing declines and spiritual needs increase at transitions in care, such as diagnosis, initiation of chemotherapy, or transition to hospice (Murray et al., 2007). Compared to patients with cancer, patients with heart failure tend to have lower spiritual well-being (Bekelman et al., 2009). Patients with heart failure experience deeper isolation and a sense of abandonment by their providers (Murray et al., 2004). Any efforts to implement holistic palliative care for patients with terminal heart failure that includes spiritual care would lack the theoretical foundation necessary for addressing spiritual suffering and facilitating spiritual coping.

Previously developed and tested interventions have drawn on the theory of self-transcendence (Reed, 2014) and the stress-appraisal-coping model (Folkman & Lazarus, 1984) to develop the intervention components and structure. The theory of self-transcendence was constructed in the framework of developmental theory and describes how individuals expand personal boundaries interpersonally, intrapersonally, transpersonally, and temporally to move beyond vulnerability to a renewed sense of wellbeing (Reed, 2018). This theory employs concepts of spirituality but lacks the specificity needed to direct patient care and intervention development for patients with terminal heart failure. The stress-appraisal-coping model (Folkman & Lazarus, 1984) also provides a commonly used framework for

understanding how patients cope with stressors and includes the concept of spiritual/religious coping. The stress, appraisal, and coping model does not provide a process model to specify how spiritual coping evolves or what specific mechanisms are present in patients with terminal heart failure. Interventions informed by theory have a higher level of effectiveness than those that are not (Painter et al., 2008). When a theoretical foundation is not well-defined, poor specificity of intervention components can result, and often hypothesized outcomes cannot be achieved (Sidani, 2015). To create effective spiritual coping interventions that are specific to patients with terminal heart failure, it is essential to develop a theory of spiritual coping in heart failure drawing on the experiences of patients who are in heart failure.

This study derived a model of spiritual coping in terminal heart failure based on narratives of spiritual coping related by patients with terminal heart failure. Narratives are a sequential linking of experiences shaped by a person in the context of an audience to communicate meaning, values, morals/ethics, and experience and may be used to persuade or motivate future action or behavior in oneself or others (Gubrium & Holstein, 2009; Riessman, 2008). Narratives provide data in the form of plotted accounts of experience in which storytellers assign meaning to what they lived through. In this way, the data represent an informant's perspective on reality, usually organized with attention to context and some form of temporal structure (Gubrium & Holstein, 2009). There is often no exact correspondence to be found between a story and facts in the real world. The point of analyzing narrative in narrative inquiry is to gain an understanding of how persons perceive their experiences and how they organize their perceptions, feelings, and beliefs. Narrative opens a view of the research participant's inner world, indicating how they understand and

psychologically manage their experiences. Validating what a storyteller reports against real events can be useful in some contexts, but the information it provides is of a kind (i.e., does the narrator have delusions? Does the narrator lack knowledge about something?) that lies outside the scope of this study. For this study, the question I asked centered on how participants organize events and relationships to construct and convey meaning (Riessman & Quinney, 2005).

Theorists have speculated that narrative is a nearly universal impulse that answers a human need to create order and meaning out of disparate, sometimes non-linear raw experiences (Riessman, 2008). In this study, I worked from the understanding that narrative-based meaning-making functions as a form of individual theorizing about experienced reality. Through the act of narrating, participants created a schema of their reality that included their perception of the cause-and-effect relationships and processes that contributed to their present state of being or self-understanding. My purpose was to analyze narrative accounts of spirituality in patients with terminal heart failure to understand what light their meaning-making within narratives would shed on the process of spiritual coping. Synthesis of these narrative's shapes, or as I call them, plots, and their meaning-rich content enabled me to formulate a model of spiritual coping in terminal heart failure.

Methods

Setting, Study Recruitment, and Sample

Participants were recruited from a Midwestern, academic, Level 1 trauma health center. Inclusion criteria were terminal heart failure defined as having a diagnosis of heart failure class III-IV (New York Heart Association functional classification) as indicated in the medical record, ability to speak English per the primary language indicated in the medical

record, not suffering from memory or cognitive impairment by a score of 25 or greater on the mini-mental status exam, ability to complete a one to two-hour interview, and ability to satisfactorily and independently complete the consent process. Exclusion criteria were no diagnosis of heart failure or heart failure class I-II, inability to speak English, inability to complete the consent process independently, memory or cognitive impairment, or inability to engage in extended interview dialogue. The nursing supervisors and the heart failure nurse navigator working in the hospital's cardiovascular units identified potential participants and gave them a brief overview of the study aims and commitments based on a prepared flyer. If a patient expressed interest in participating, the nurse navigator informed me of this. Then, I screened and consented them in the hospital room before discharge, collected demographic data, and conducted a mini-mental status examination. When COVID restrictions were put in place, limiting hospital access, the recruitment was expanded to include postings to social media heart failure support groups. Social media posts encouraged interested individuals to contact me directly through my university-hosted email address. In a follow-up email, they were provided with a description of the study and asked to sign and return the HIPAA authorization form. One participant was recruited and interviewed with this approach. Convenience sampling was used, though I also tried to achieve some variability of religious orientation and sociocultural background in the sample.

I offered participation to 53 individuals. Fifteen agreed to participate, but five were unable to enroll because of their declining medical condition or were lost to follow-up. I attempted to sample for maximum variation based on age, gender, and religious identity. The medical records of potential participants were reviewed, after obtaining the HIPAA authorization form. Some potential participants were not approached for participation

because their age, gender, and religious identity closely matched participants who were already enrolled.

Data Collection

I conducted one video conference interview in July 2020 and all other interviews in-person July 2020 - December 2020. I followed narrative interviewing practices as outlined by Jovchelovitch and Bauer (2000), using open-ended questions posed in a conversational style that allowed participants to expand freely and follow their narrative leadings (Gubrium & Holstein, 2009; Riessman, 2008). After a brief explanation of the study, I invited participants to "tell me your spiritual journey. You can start at any point in your life." Follow-up questions included requests for more detail and leading prompts, such as, "Some people say that things change after they become sicker, others say it does not make much difference. What about you?" and "How has spirituality impacted you during your illness?" See the interview guide in Appendix E. The interviews were audio-recorded and transcribed. I also wrote field notes after each interview to capture the interview setting, comment on the non-verbal and para-verbal communication techniques the participant used in the interview, and add reflective commentary on the major points of the narrative and my initial impressions (Mulhall, 2003).

Originally, I planned to schedule interviews with participants after they had been discharged from the hospital in a more private setting like the participant's home. However, because of COVID restrictions, four participants were interviewed in their hospital rooms. All other interviews occurred in the participants' homes, following the original study plan.

Data Analysis

I followed a multi-layered, iterative approach to data analysis. The first layer of analysis utilized narrative content, structure, and thematic analysis techniques based on Riessman's (2008) description. In this layer, I labeled sections of the narrative for repeated narrative features such as thematic repetitions, points of emphasis, and plot structure as well as particular divergences in any of these within interviews. I wrote memos along the way to record how the themes seemed to be coalescing into a picture of spiritual coping for that narrator (Nowell et al., 2017). Second, I linked my field note observations to segments of the narrative data and my memos. Then I considered ways in which each narrator's interview conveyed meaning in the holistic context of their narrated environment. Third, I read across the interviews for similarities and differences in content and structural themes, particularly plot structure. In the fourth and final layer of thematic analysis, I reread the patterns I had identified against the interviews to confirm that my interpretations maintained fidelity to the narrative wholes they recorded. Throughout the process, I discussed the results with a second reader who has expertise in narrative inquiry and qualitative data analysis and is familiar with the data and purpose of this study.

Ethics

This study was deemed exempt by the Institutional Review Board at the University of Missouri-Kansas City (UMKC) with an interagency agreement by the University of Missouri-Columbia (Approval No. 255542). REDCap, an encrypted database on the secure UMKC server, was utilized for data management to ensure confidentiality. Participants were given pseudonyms to protect privacy and confidentiality. Participants were informed of potential risks including psychological distress and offered counseling services to address

any potential issues. I was qualified to conduct this study, having been trained in narrative inquiry techniques, narrative interviewing, and mental health nursing.

Rigor

Rigor in qualitative research, because of the naturalistic setting, emergent design, and the researcher as the instrument, continues to be a controversial issue (Denzin & Lincoln, 2018). Though quantitative validity criteria cannot be directly applied to qualitative studies, there remains a need to assure readers of the trustworthiness of the data and interpretations (Riessman, 2008). In this study, I used three criteria specific to narrative inquiry provided by Riessman (2008): correspondence, coherence, and persuasiveness. Correspondence refers to the idea that the narrative and its interpretation by the researcher relate to the narrative told in the interview (Riessman, 2008). Correspondence is demonstrated in this study by including narrative content to support my interpretations. Coherence is the hang-togetherness of either the narrative events or, as in this study, the theoretical coherence of the story I have constructed based on the data (Riessman, 2008). Coherence in this study is supported by outlining the methodological path, including generating data through multiple sources for triangulation and triangulation with a second reading and in the background maintaining an audit trail. Finally, persuasiveness is a feature of the researcher's interpretive conclusions and arguments. A persuasive report provides evidence that interpretations are plausible, reasonable, and convincing (Riessman, 2008). I sought to meet the persuasiveness criteria by including quoted data samples to support interpretations.

Results

Sample Characteristics

The final sample included 10 participants. Demographic data for the 10 participants who completed the study are presented in Table 1.

Table 1
Sample (N=10) Characteristics

Demographic Category		**N (%)**
Age	Range: 29-83	-
Sex	Male	40%
	Female	60%
Religious Preference	Protestant-Christian	70%
	Spiritual, not religious	30%
Spiritual/Religious Gathering Attendance	None: 4/10	40%
	Once per year but < every 6 months	40%
	At least weekly	20%
Heart Failure Stage (NYHA)	Stage III	50%
	Stage IV	50%
Marital Status	Married	70%
	Single/Widowed	30%
Race/Ethnicity	White	90%
	African American	10%

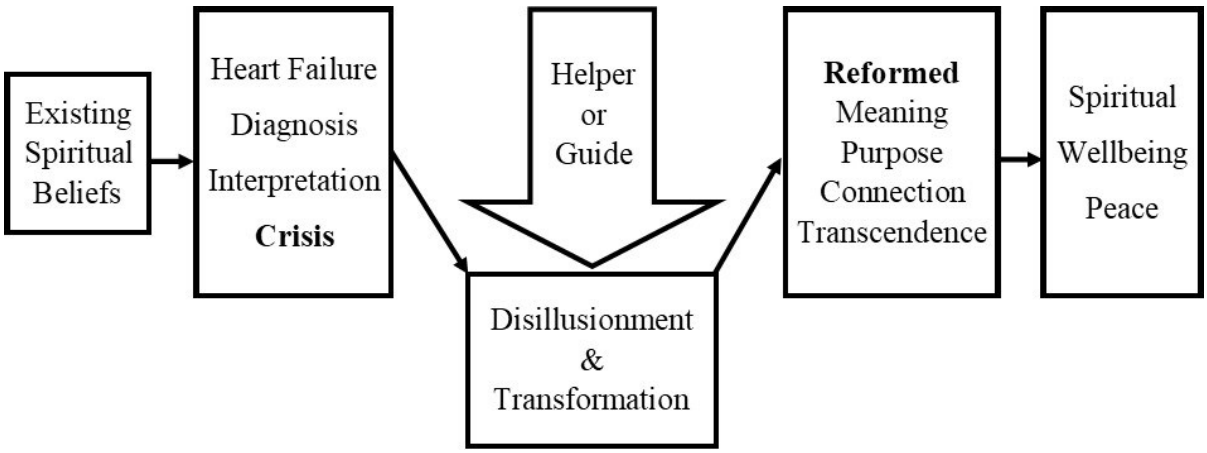
Half the participants identified themselves as spiritual but not religious, while the other half claimed affiliation to several Christian denominations. Participants varied in age 29-83 years, (mean 64.9 years), and time since diagnosis (from 1 week - > 3 years). Time since diagnosis was not collected as a specific variable, but relative times were discussed by participants within the interviews. There was less diversity in the sample in terms of race/ethnicity and

socioeconomic background. Nine participants were White; none were Hispanic, and only one was African American. All but two participants were of middle or low income.

First Stage: Plot and Theme

In the first stage of analysis, I noted how individual accounts of spiritual coping in terminal heart failure followed three main plots, each with its own characteristic themes. In the first plot, narrators constructed a story of spiritual coping in heart failure that followed a transformative pattern in which illness challenged a person's existing spiritual beliefs, precipitating a crisis and the eventual replacement of the existing beliefs with new ones (Figure 2).

Figure 2
Heart Failure as a Spiritually Transformative Experience



Common themes in the transformative pattern included *illness and spiritual crisis, the helper or guide, spirituality as personal and pragmatic, reformed connections,* and *finding meaning and purpose through service* and *gratitude*. Representative data for each of these themes are presented in Table 2.

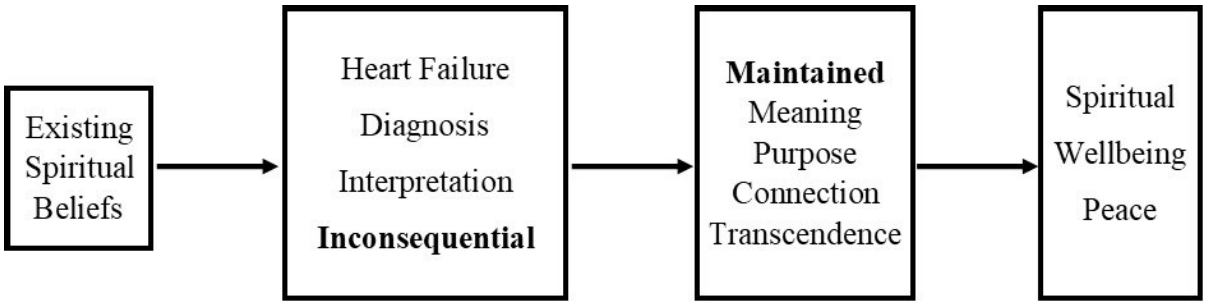
Table 2
Heart Failure as Transformative Key Themes

Illness and spiritual crisis	Angie: So, I grew up in a very Christian household in the South, so of course in the Bible Belt. I came to realize in high school and college, when I got sick, that disability and being sick kind of has this timeline. They expect you to be better and then move on. So, I left the Baptist Church. In my twenties, I got sicker and sicker. More and more people would invite me to different churches or invite me to different religious things. I just kept finding the same, "Oh, you have this health problem" [or] "When is it over?" or "You're too young for that," or "Pray it away," or that I need to find some spiritual thing to just automatically fix me. Mary: Mortality—it slapped me in the face. Wow, your heart is messed up. That's sort of a serious thing. The other thing is you've caught me in a big - not crisis of faith - but a metamorphosis of faith.
The Helper or guide	Angie: [I] had a therapist and she was more spiritual. She's the one who kinda got me back into [spirituality] because the way she approached it was, "Hey, go explore this and see how you feel and if you don't want that, that's fine. But if you do, okay you found something that helps you." I think that's really how I got back into [spirituality] was being pushed to go try [things] and see what made me feel better, see what helped. There was no making me feel guilty for leaving the church.
Spirituality as personal and pragmatic	Mary: God is love he's not a God of punishment. He's not waiting there for you to screw up again. And with that concept, I had the strength to step back from the church. Because some of it [church doctrine] I believe and some of it I just, I'm sorry, hands down, can't get with. That's the time where it totally shifted to where I felt like I wanted a real relationship with God.
Reformed connections	Angie: I made more connections with people that I found through support groups or my close friends who have sort of the same history as I do. I'm fine with having those few connections that are really good instead of having a lot of connections that are just acquaintances.
Finding meaning and purpose through service to others.	Angie: I had to go more towards [finding] meaning. I got dealt the crappy hand of genetics and health for a reason--so I can help others.

Maintaining gratitude	Mary: All I know is that when I pray, I'm more likely to offer up gratitude than I am to ask for help.

In the second plot, the participants narrated stories of spiritual coping in heart failure that followed a spiritually integrative pattern in which participants brought new spiritual realizations and experiences into their existing beliefs, often with comparative ease (Figure 3).

Figure 3
Heart Failure as a Spiritually Integrative Experience



The themes that were prominent in this plot were the *centrality of formative experiences, meaning found in a benevolent higher power or philosophy, sharing wisdom and a legacy, a service ethic, a focus on gratitude,* and *heart failure as inconsequential*. Representative data for these themes are presented in Table 3.

Table 3
Heart Failure as Spiritually Integrative Key Themes

The centrality of formative experiences	John: I have always been a spiritual person. I was raised that way. My mother and father were very spiritual. Never seen them drink, never heard them cuss never seen them smoke, just peaceful people. I observed that a lot. And that was the way I intended to live my life. Bill: I'm not a particularly strong religious person. One of my uncles was an evangelical preacher, and Hellfire brimstone, very southern Baptist. I don't look at religion that way. I don't

	think it should be structured. When I was young and, on the tractor, driving for five or six hours, and thinking about things - once in a while, I'd say, “You know, this just didn't appear out of anywhere. Something caused this to happen.” I do believe that there was Jesus Christ, I do believe that there was meant to be a format, but I also believe that the teachings of the Old Testament and some of the New Testament was more about social control, mental and social control.
Meaning found in a benevolent higher power or philosophy	Peter: I'm not afraid to die. I believe that we do continue because I was thinking about, well, is there life after death? Then the question came, if not, then what's the purpose? God doesn't waste things, or the creator doesn't waste things. So there has to be some continuity because otherwise there'd be no purpose.
Sharing wisdom and a legacy	John: Now they see that the love they received they out there to give love. You know, you think they wasn’t listenin’. The youngest one, he said, “I got a neighbor down the street that ain't doing good.” I said, “Pray for him and go down and check on him.” He said, “I cook every day then I take him food down. He said, ‘I feel good about it. Every time I do it, I think about you. I use to tell you why you do people like that?’ He said, ‘I understand it better now.’
A service ethic	Jill: There was a guy that worked in the parking lot where I worked. He worked hard cleaning cars. It was coming near [his son’s birthday] and I had him take care of my car. I made sure that I shared with him so that his son would be taken care of. I remember asking him, so these guys that drive these fancy cars, do they give you a very good tip? “No, they don't tip at all.” It makes me much happier to be able to make sure a little kid’s gonna have a good birthday rather than be so greedy. Stuff might give you a feeling for a little bit but the newness and all that’s gonna wear away pretty soon.
Focus on gratitude	Ron: I don't like to be around people that's negative. You can never accomplish your goal by being negative. John: It’s a blessing to have the place. I want off the steps because I can't get up and down. But I've got a place. Everything I need. I don't need for nothing. I wished I could get my health together so I can enjoy it more. But I'm enjoying what I got while I can.

Heart failure as inconsequential	Bill: I have had many close calls and not gotten a scratch from them. My heart issue, once I found out because I was already used to losing this eye, when they told me, "Well, a third of your heart's dead. There's nothing we can do for that." My stupid response was, I don't care, as long as I can get up walking to go quail hunting, I don't care.

The narrators who offered accounts that followed the third plot described a pattern in which heart failure posed such a profound challenge to their spiritual wellbeing that neither new nor integrative forms of spiritual coping could be identified. Instead, this plot traced a disintegrative trajectory and featured themes of *everything broke* with subthemes of *physical and spiritual wellbeing,* and *lost connections* (Figure 4). Representative data for these themes are presented in Table 4.

Figure 4
Heart Failure as a Spiritually Disintegrative Experience

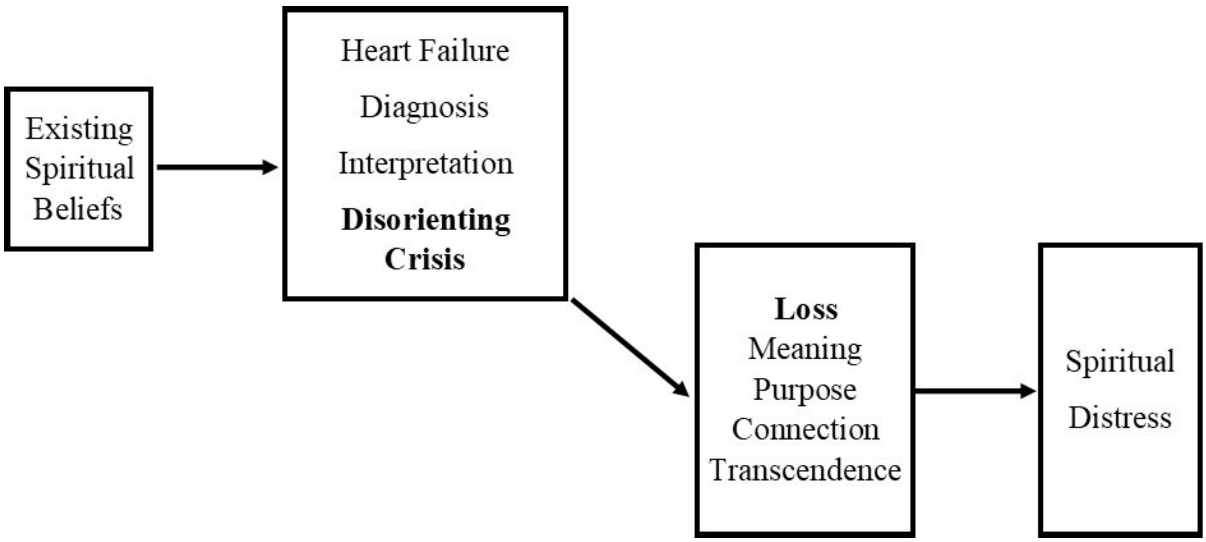


Table 4
Heart Failure as Spiritually Disintegrative Key Themes

Everything broke	
Physical and spiritual wellbeing	It pretty much upset me to find out that I had diabetes and scared me. Spiritually, it just brought me down. Sad. But then everything [e.g., physical health] started going wrong and never got any better. It just keeps getting worse every day.
lost connections	[My sister] is my connection, and we talk on the phone for 30 minutes to an hour. Not once, it's throughout the day. But that's not the same.

Heart Failure as Spiritually Transformative

Crisis of Health and Spirituality. Two participants, Angie and Mary, described their experience of heart failure as a transformative experience. Angie's story began:

> So, I grew up in a very Christian household in the South, so of course in the Bible Belt. I came to realize in high school and college, when I got sick, that disability and being sick kind of has this timeline. They expect you to be better and then move on. So, I left the Baptist Church. In my twenties, I got sicker and sicker. More and more people would invite me to different churches or invite me to different religious things. I just kept finding the same, "Oh, you have this health problem" [or] "When is it over?" or "You're too young for that," or "Pray it away," or that I need to find some spiritual thing to just automatically fix me.

Angie's transformation took place over time, extending across decades as her illness evolved and her ability to cope with her religious community's responses also shifted. Eventually, as

we see below, the tensions between what she was experiencing in her illness and what she needed to find in her spiritual community led to the transformation of the latter.

Mary, too, related the experience of religious disillusionment, in her case leaving a previous religious affiliation. But in Mary's narrative, that process was sudden and served to accentuate or clarify the meaning of an ongoing spiritual reevaluation. Mary connected the events of illness and religious realignment in a personification of death in which she was struck by the momentousness, the profound seriousness of the linked changes in her life: "Mortality—it slapped me in the face. Wow, your heart is messed up. That's sort of a serious thing. The other thing is you've caught me in a big - not crisis of faith - but a metamorphosis of faith." Mary's account of religious transformation, even with its rhetorical reduction to "another thing," underscored how her heart failure was if not the occasion for at least contiguous to the reexamination of her faith – an ultimately her religious affiliation.

Both Angie's and Mary's trajectories included co-occurring challenges of illness and spirituality that were characterized thematically by crisis and disillusionment. Mary's section metaphor for death is a suggestive indication of this theme. At one point, she asked, "Have you seen those hourglasses that the sand drips through?" And then went on to add, "I feel like there's more sand on the bottom than there is dripping from the top." This glass-half-empty observation draws attention not only to Mary's awareness of the insistent, unrelenting cumulation of mortality, of growing time-spent next to diminishing time-to-come, but also the culmination of failures, the course of heart failure itself, a spiraling of illness certainty and spiritual uncertainty into one threat.

Angie too described disillusionment with her church in the context of mounting illness, an experience of crisis that created an absence, a nullity in her life that intensified her

suffering: “I think once I left the church, I was really just angry. I was just like, no spiritual, no religious, nothing. That didn’t work because it made my anxiety worse. [I] didn’t get any sort of positive outlook on life at all. No reason, no meaning.” Negation is the keynote – no spiritual, no religious, no reason, no meaning, nothing. For Angie, leaving the church was an act of anger that cascaded into disconnection from others, from her purpose, from her sense of self-worth, and her understanding of God. She explained, “If there is something bigger than me then my experience isn’t all there is in the world. I don’t know, that’s about as far as I get.” This is a change from her earlier life experience: “I grew up in a very Christian household. We were in the South so of course in the Bible Belt.” By this statement, she was implying that she previously held a more literal or fundamentalist view of the Christian God as the higher power, but her spiritual disillusionment pulled her back from that narrower conception of a higher power to “there is something bigger than me.”

Angie’s description of a cascade into disconnection from others, purpose, and sense of self-worth was echoed by Mary: “Now that I've walked away from the church, am I really worthy enough to [say], ‘Help me?’ That causes me a lot of anger at the church. I am just not emotionally connected. It compiles my isolation even worse.” The faltering sense of spiritual connection meant a diminished sense of belonging and communion that was felt in relationships like those with friends who, as Mary said, “Over time, you know, [those church friends] just sort of fade away.”

For both women, the result of this combined crisis of illness and spirituality brought about a split from the community in which they had formerly found belonging and purpose. Both women expressed anger within this crisis, but Angie added a note of sadness, even betrayal as when she described how her church came to see her disease as signifying

judgment for her sins or a consequence of her lack of faith. The trajectory of transformation in both Angie's and Mary's experience began with a crisis that deepened as heart failure and spiritual disappointment became increasingly intertwined.

Encountering a Helper or Guide. In the interviews that followed a transformative patter, at the height of disillusionment and disconnection, the heart failure patient encounters a kind of helper or guide that facilitates the transformation of spiritual crisis to spiritual coping. In Angie's interview, the helper or guide took the form of a psychotherapist who introduced Angie to a more open approach to spirituality. The therapist's message was simple but for Angie novel and illuminating. She told Angie, "'Hey go explore this [spiritual exercise] and see how you feel and if you don't want that, that's fine. But if you *do*, okay, you found something that helps you.'" The experimental and pragmatic approach was new ground for Angie, one with obvious advantages over her earlier experiences in a church whose answer to illness was, '"Pray it away,"' and when that did not work settled for "making me bad for where I was." The helper or guide in Angie's narrative was a person who triggered a transformation in her journey by presenting spirituality to her as a project, a realm for exploration, and a tool for wellness. Angie stressed how starkly different this approach was from her former understanding of spirituality as inflexible, judgmental, and accessible exclusively through formalized religion. Through the transformation that followed, spirituality became more personal and pragmatic for Angie.

The helper or guide in Mary's case took form not as a person, but as an assignment in a psychology course, where she was required to write "a blessing journal, with three blessings a day." Mary said that she "carried that [journaling] on for almost 10 years now. That is the strongest thing that I practice now – is gratitude. That makes the biggest

difference in my sense of peace." Like Angie's helper or guide, Mary's led her to see that she could branch out and find new ways to practice spirituality, ones that lay outside the church and replaced its constrained, unhelpful, alienating messages with liberating, constructive, personal, and pragmatic ones.

Outcomes of Transformation. The endpoint in the transformations plotted in Angie's and Mary's narratives were rendered thematically as *fewer but deeper connections, renewed purpose through clarified meaning,* and *gratitude and a positive perspective.* For both women, the crisis of losing ground to heart failure and losing communion with church connections meant a contraction of their worlds. In the aftermath of these losses, both women formed new circles of connection that were smaller than before but also deeper. In one instance, Mary shared how difficulties in her relationship with her daughter pointed to parallels in her relationship with her God:

> God's supposed to be pure love. And if I love this child, *this* much, and I'm sad for her having to try to learn this lesson again and again, how much more so, with his greater love, does he care for me when I'm in my situations, whatever they are? His love is bigger and more infinite than what I can feel.

It was at this point, Mary says, she was spiritually transformed, ready to "shift" from a spirituality focused on rules to one centered on relationships. She closed her story saying,

> I had the strength to step back from the church because some of it I believe and some of it I [couldn't] get with. [Those] sweet ladies [were] all happy and they were saying their beliefs to each other over and over. I didn't want to ruin their meeting, so I quit going. That's the time where it totally shifted. I felt like I wanted a real relationship with God.

Both women described finding new connections or revaluing family members and friends, and both narrated a process of drawing closer those who were more likely to share or support their reformed spiritual beliefs. Mary's spiritual transformation moved her away from connections with her previous friends in the church community but toward new relationships and connections, including a deeper appreciation of her family ties. At one point, Mary offered, "I have a lot of good Facebook friends, you know, but just not hardcopy friends." For Mary, heart failure led her to bring renewed attention to the "hardcopy" connections she did have, those ties that were immediate and close, like her grandchild and immediate family: "When I hold that baby [grandchild], he brings me a lot of peace. My kids, my husband."

Post-transformation, spirituality was often characterized by the women as a medium in which the meaning of heart failure in their lives was crystallized, leading them to a new sense of purpose or direction. As Angie put it, amid illness, "I had to go more towards [finding] meaning. I got dealt the crappy hand of genetics and health for a reason--so I can help others." With the assumption that there is "a reason," behind heart failure, the challenge of illness, that of transforming the experience into a new purpose. Angie described how she met that challenge by providing medical specialists who treated her with information about geneticists who could run immunology tests for diagnosis. Her experience has had an impact: "Now my immunologist uses [genetic testing] quite frequently in his practice," which might mean "someone else get[s] their diagnosis sooner than me," thus preventing "them from ending up where I have." Mary similarly described how her journey left her feeling newly motivated to meet the needs of her family and specifically her autistic son: "My autistic son can't handle any change. Leaving him is gonna be a terrible experience for him. He's not ready yet. He's getting ready, little pieces by little pieces." Facing her mortality and worried

about her son's future without her, Mary found purpose in preparing him for life on his own. This was a purpose Mary contrasted with a darker alternative, the despair and depression she struggled with before her spiritual transformation: "I could be in a position where I could let myself just go deep and dark down the black hole, in depression, but I look back now with a clear head and see how that affected my family. I don't want to do that to me or them." In Mary's narrative, suffering was transformed into a basis for coping, embodied in a renewed sense of connection, meaning, and purpose, that of preparing her son for life without her

As described above, Mary found that keeping a daily journal was the helper or guide that opened her to a renewal of spirituality, by consistently focusing her attention on gratitude. Angie, too, found that gratitude became a key element in her transformed spiritual life, observing, "I wouldn't be where I am today. I wouldn't have met my husband or my stepdaughter or be where I am at all if it wasn't for my health. So, I guess it's just my way of trying to see a positive outlook when I get [a] bleak report back." In the crisis experience of illness, gratitude – in Angie's case, *toward* the illness – and the more positive perspective that came with it became key to coping with difficult news. In some ways, the focus on gratitude helped both women transcend the immediate struggle and move toward a more expansive view that encompassed not just the bad but also gratitude for the good.

Angie and Mary described the uniquely devastating event of heart failure in which a gradually unfolding but overwhelming crisis led to rejection and then renewal of spirituality. With the assistance of a helper or guide and through various setbacks and new challenges, both Angie and Marie traced a narrative plot that passed through crisis to end in transformation. Both described a new spirituality characterized by deeper and closer connections, clarified meaning for the crisis of heart failure, and a sense of purpose newly

grounded in gratitude and service to others. Of the three plot types represented in the interviews, *heart failure as transformative* appeared to be most associated with peace and wellbeing for the participants who followed it.

Heart Failure as Spiritually Integrative

The second plot did not interpret heart failure as a disorienting crisis. Instead, heart failure was interpreted as spiritually inconsequential and not a threat. This approach was supported by formative experiences that narrators described as having formed their spiritual beliefs. Sometimes there was a transformative spiritual plot embedded in earlier challenges. In other cases, the narrator framed their stories with spiritual beliefs that emerged early in life and never substantively changed. For all the participants who shared narratives in this category, heart failure was less a rupturing event that precipitated a spiritual crisis than a life challenge that occurred within the context of formed and stable spiritual beliefs. The integrative plot was distinguished by five themes: the *centrality of formative experiences leading to formed spiritual beliefs, belief in a benevolent higher power or philosophy, giving help/service, teaching others, deep connections,* and *gratitude.* These elements characterized life experiences and spiritual beliefs that helped the participants adapt to life with a terminal illness. Heart failure was still a struggle, but something that an existing spirituality enabled participants to deal with rather than being the occasion for a disorienting crisis.

The Centrality of Formative Experiences Leading to Formed Spiritual Beliefs. Most of the narratives in the integrative narrative group placed a strong emphasis on formative experiences that gave shape to their spiritual beliefs. The description of early influences was not unique to the integrative plot, but the weight they were given and their continuing impact on the stories told was characteristic. Early spiritual influences

encompassed a variety of events and themes, including early spiritual experiences, abandonment, receiving help, and the death of loved ones. Formative experiences were both negative and positive. Some drove narrators away from organized religion while others pulled them in.

Bill, Betty, Peter, and Ron all described formative experiences with organized religion that steered their spiritual stories moving forward. Bill discussed his childhood observations of a family member who was "an evangelical preacher, hell-fire brimstone, very, very southern Baptist." Bill went on to contrast his early exposures to religion with his later spiritual outlook, saying,

> I don't look at religion that way. I do believe in Jesus Christ, I do believe that there was meant to be a format, but I also believe that the teachings of the Old Testament and some of the New Testament were more about social control, mental and social control.

Bill's formative experiences with his uncle provided a negative model or format against which he subsequently positioned his own, less fundamentalist, more personal and pragmatic spirituality. Betty also framed her spiritual beliefs around a formative religious experience, though hers was more positive. Betty described,

> When I was in high school, I decided I would join the church, and I would be baptized. My sister said, "Would you mind if I come along?" So, both of us were baptized for the first time. That was important to me that she wanted to do that.

Betty's formative experience with religion solidified her close connection with a sister, a relationship she later described as a critical source of ongoing spiritual support. Betty also maintained a strong connection to the organized Christianity of her early years, repeatedly

describing religious belief as a component of her spiritual coping and a helpful framework for interpreting difficult life experiences.

Formative experiences with relevance to spiritual development also occurred outside of religion in challenging transformative life events. For example, Ron and John talked about the experience of early abandonment by their parents. For both, the help they received from others prompted an altruistic response. Ron related how

> My dad ran me off when I was 14 because I didn't agree with him. He, he told me hit the road and I said bye about 12 o'clock at night. Next morning, I went up to this old man and I told him, I needed a job. He said, "You know, I'm gonna take a chance on you, I think I'm gonna hire you." They were good people. In fact, they took care of me like I was one of their kids.

Ron's life philosophy, "there are givers and there are takers," was developed early in life based on his experiences of receiving aid from others. Ron came back to the theme of giving throughout his narrative, including amid the story of his own suffering in heart failure: "Don't be grouch ass. You treat the [nurses] nice because they're trying to take care of you. It's just easy to say, 'You do a great job.' That makes [a person] feel better." Being on the receiving end of an other-oriented approach early in life provided Ron with a model for living, a moral structure founded on connection and gratitude that was integral to the way he coped with heart failure.

Ruth's narrative described a similar commitment to the needs of others while also revealing the limits or costs that such giving might incur. Ruth's story revolved around caring for others, including time spent providing care at different points to two husbands who grew sick and died. This story reached its climax in one day when she developed chest pain

and ended up in the hospital. Ruth described how, as the doctors examined her, her daughter came to the room asking Ruth how and when to give her father an injection he needed. Ruth said, “The doctor heard this whole thing, and she looks at me and she said, ‘I know what's wrong with you. It's nothing. Just nerves. Stress is coming down on you. Like everybody depends on you, don't they?’” Still in the hospital, Ruth prayed, “‘God, you know, you just have to help me through this. Because these people can't take care of themselves. And there isn't anybody else to do it but me and I have to be able to do what I can.’” Ruth related that the next morning, “I got up and I was fine. Nothing ever happened after that, you know, I was just fine. But I know it was through God.” Amid her own acute need, Ruth was reoriented by the physician, who recognized the source of her symptoms in the self-sacrificing role she assigned herself. If we expect this story to end with Ruth recognizing the harms of taking on too much, that expectation is unfulfilled. Ruth’s story ends with prayer and validation: God answered her plea with a restoration of health that allowed her to resume her service-oriented role. For Ruth, the story was not about taking on too much or even about letting God do more but about how she could count on God to provide *her* with the strength to do more.

Stable Spiritual Beliefs. The formative experiences of those who followed the integrative pathway provided a stable foundation on which they relied when faced with a heart failure diagnosis. In their narratives, Betty, Ron, Ruth, Jill, and Peter integrative heart failure into pre-existing spiritual beliefs rather than interpreting the illness as a monumentally disruptive challenge or threat. Though not all the same, the integrative narrators described spiritual beliefs that tended to include belief in a higher power or philosophy that served as a source of existential assurance and meaning, the importance of strengthening and building

connections with others, the importance of living a life of giving, and the importance of practicing gratitude.

Meaning Through a Benevolent Higher Power or Philosophy. All of the participants who shared a narrative of integration referred to God, a higher power, or philosophy as a central part of their spiritual beliefs. The higher power or philosophy provided a benevolent controlling influence over life, bringing stability and meaning to otherwise chaotic, inexplicable events. Peter's perspective of a higher power stressed how the nature of God is conservative (i.e., not wasteful) and proof that death was not the final word, that life has a purpose beyond itself:

> I'm not afraid to die. I believe that we do continue because I was thinking about, well, is there life after death? Then the question came if not, then what's the purpose? God doesn't waste things, or the creator doesn't waste things. So there has to be some continuity because otherwise there'd be no purpose.

For Peter, the higher power was benevolent and instructive. Contrasted with Mary's harsh "mortality" or the impersonal figure of an hourglass, Peter's benevolent God or creator enabled the integration of illness, death, and loss into larger meaning. Death is no intransigent and empty sign, but a moment opening up to continuous life. Peter's higher power underwrites a logic ("So there has to be") that refutes the idea that death is an end or that life is a waste by integrating suffering into a grander purpose. For Ron, the philosophy of givers and takers described above, provided an orienting perspective that helped him interpret the actions of others as well as pointing him toward meaningful actions for himself.

Connections, Giving, and Gratitude. The other shared themes in the integrative plot were *strengthening and building connections with others, living a life of giving*, and *practicing gratitude*.

Connections. Participants who integrated their experience of heart failure into existing spiritual beliefs emphasized not just how their beliefs sometimes grounded a connection with a higher power but also enabled them to strengthen and build connections with friends and family even in the face of life-threatening illness. In her hospital bed, Jill reflected on the things she valued most in life saying, "I feel like I have some really great relationships that people will never experience. [These relationships] are far greater than any money could ever buy." Ron related his belief in life as a transitional state in which his connections with people were important but also transient, giving way to his future with God: "I'm at a point in my life to where I may have today with you and tomorrow with God." Participants in the integrative plot group dwelt on how meaningful relationships with friends and family were enjoyed for what they were, acknowledging limitations but resting on the positive effect those relationships had in their lives.

Giving. Participants also consistently related an ethic of service or giving to others as a component of spiritual beliefs that withstood and absorbed the spiritual challenges of heart failure. Participants described how continuing to give to others after diagnosis through kind acts and gifts of service helped them shift from a perspective focused exclusively on loss to one that was focused on the wellness and joy of others. Acts of giving facilitated the participants' discovery of new, positive ways of relating to life. This was the case in Jill's recollection of a small kindness, performed early in her diagnosis, that likely brightened the day of everyone involved:

> There was a guy that worked in the parking lot where I worked. He worked hard cleaning cars. It was coming near [his son's birthday] and I had him take care of my car. I made sure that I shared with him so that his son would be taken care of. I remember asking him, "So these guys that drive these fancy cars, do they give you a very good tip?" "No, they don't tip at all." It makes me much happier to be able to make sure a little kid's gonna have a good birthday rather than be so greedy. Stuff might give you a feeling for a little bit but the newness and all that's gonna wear away pretty soon.

Other-oriented giving seemed to lighten the load, bringing happiness, as Jill demonstrated, both to the giver and receiver. In another example from the integrative narratives, John related how he inherited a legacy of love and service from his adoptive parents and community and then passed that legacy to others. John depicted his practice of taking in young men who, like him, were abandoned by their families, showing them kindness, and teaching them to become men who would respond to the needs of others:

> Now, they see the love they received, they out there to give love. You know, you think they wasn't listenin'. [But then the] youngest one, he said, "I got a neighbor down the street that ain't doing good." I said, "Pray for him and go down and check on him." He said, "I cook every day then I take him food down." He said, "I feel good about it. Every time I do it, I think about you. I used to tell you, 'Why you do people like that?' He said, "I understand it better now."

John took the wisdom he gained from observing the generosity of his adoptive parents, lessons about focusing on the needs of others, and taught that ethic to his adopted sons. He said that when he struggled with heart failure, knowing that his adopted sons were carrying

on this legacy helped shift from a self-focused orientation to a broader perspective in which his problems seemed less overwhelming. The shift from self-focused to other-focused might also be framed as a kind of transcendence. If we conceive of transcendence as simply moving beyond the immediate, perceptible circumstances into a realm outside of a person, then these acts of other-oriented giving do appear to help narrators achieve such a state.

Gratitude. The participants who narrated stories of integration frequently referred to the world as a benevolent place that invoked feelings of gratitude. For example, when Betty was asked what advice she would give to others she responded, "Just live your life as well as you can. Enjoy it. Enjoy [the relationships]." The perspective of gratitude was evident in both John's and Ron's discussions of the practice of gratitude and its role in bringing a sense of peace. John reveled gratefully in having a home:

> It's a blessing to have the place. I want off the steps because I can't get up and down, but I've got a place. Everything I need. I don't need for nothing. I wished I could get my health together so I can enjoy it more. But I'm enjoying what I got while I can.

Gratitude for other simple pleasures such as hunting art, gardening, and music, played a role in the narratives of Bill, Jill, Betty, Peter, and Ruth. These participants described how activities they loved made their lives richer so that even while suffering they were able to turn attention from life's cruelty to its richness and beauty. For Ruth this was about "flowers, all kinds, it doesn't make any difference what they are. From the first moment I planted the first pansies, I was just in my happy place [chuckles]. And every flower thereafter just made it more so." Participating in creating something of beauty (for Ruth "I planted") brought Ruth out of the challenges of heart failure into her "happy place." Ruth's immersion in the creative process of planting and growing flowers represented a kind of transcendence. Asked directly

when she had felt a *lack* of peace after her heart failure diagnosis, Ruth responded, "I really can't think of anything. There is no time." For Ruth, heart failure was a new reality in her life, but it was one that she could accommodate into her existing beliefs and practices – because she had no time to do otherwise.

Outcomes of Heart Failure as Spiritually Integrative. Ron, Jill, Peter, Betty, Ruth, John, and Bill met heart failure with a set of spiritual beliefs already in place. Their narratives developed around existing beliefs that were carried forward from earlier formative experiences and that were expressed in spiritual themes of strengthening and building connections, living a life of giving, and practicing gratitude. As a trajectory, the integrative plot illustrated how beliefs in life's richness could enable those who experienced terminal heart failure to gain leverage over disease. As Bill said,

> I have had many close calls and not gotten a scratch from them. My heart issue, once I found out, because I was already used to losing this eye, when they told me, "Well, a third of your heart's dead. There's nothing we can do for that." My stupid response was, I don't care, as long as I can get up walking to go quail hunting, I don't care.

Heart failure was important but only as one among many "close calls," challenges that Bill took in stride. Similar to Ruth, Jill, and the other integrative narrators, the diagnosis of heart failure did not challenge Bill's patterns of belief or systems of coping but provided another opportunity to exercise them.

Sense of Peace. For narrators who had a spiritually integrative experience of heart failure, the outcome was often described in terms of peace. There might be a fear of suffering and, as Bill said at one point, all was not "roses and cookies," but mortality was accepted as part of the mixed bag of life: "You've got some unpleasant things," Bill observed, "and then

you've got things that you just can't wait until it happens." Betty expressed a similar sentiment: "I'm not gonna let this stop me or slow me down. I might walk a little more slowly, cough a little bit more, or something. But, to me, I haven't changed." The integrated narrative of heart failure was characterized by this attitude of equanimity, in which both the good and difficult in life were accepted as part of the whole. When I asked Betty about her heart failure, she responded by saying, I'm not worried about it, except that it takes my breath, and I'm not able to move around like I once did. That's kind of scary. But [long pause] when I go, you know, it's alright. I'm not concerned about dying." Like the heart failure itself, death from heart failure was part of the fabric of life. Hence, even with the "scary" loss of breath and mobility, Betty found peace in the conviction that "when it's your time, it's your time," that you, "do as much as you can," and when your time is done, "then you have to accept it." In the integrative plot, participants' beliefs about life's purpose, often emanating from faith in a benevolent higher power; the importance of connections with and giving to others; and the perspective gained through a practice of gratitude provided participants with a broader perspective that brought peace during persistently declining health.

Heart Failure as Spiritually Disintegrative

In the third narrative type, heart failure was a devastating event that initiated a physiologically, psychologically, and spiritually disintegrative trajectory. The crisis of heart failure in the disintegrative plot was in some respects similar to that depicted in the transformative plot. In both types, the story revolved around the shattering onset of illness. But in the disintegrative plot, the narration did not include a turn or return to spiritual coping. There was no helper or guide. Instead, in the disintegrative plot, crisis was compounded by crisis.

Janet was the one participant in the study who narrated this pattern. For Janet, the story of her spiritual life in heart failure mapped to the physiological decline characteristic of heart failure. Heart failure is a disease of cyclical but progressive loss, and Janet's story emphasized the inexorability of the decline, with experiences of repeated loss and brokenness that were never resolved but only seemed to lead to more loss. Along with a growing host of physical health challenges, Janet described having to leave a highly valued job and losing ties over time with her mother, sister, and son. The downward trajectory that structured her story began with her diagnosis of diabetes in her late thirties, followed by debilitating musculoskeletal diseases, and culminating in heart failure. When asked to narrate her spiritual life in heart failure, Janet was brief: "Before I got sick, I was happy, didn't have any problems, but I've been sick for over half my life so I don't know that you can get that much from it. Let's see, I guess I would say that life *was* good." Janet could cast back to a better time, but that time was gone, scarcely worth remembering, definitively eclipsed by the event of heart failure.

Janet depicted the crisis of her diagnosis two years before as a rupture, the closing down of future possibilities. Her response to the diagnosis was: "This is over. [chuckling] I'm done." As Janet discussed the heart failure diagnosis further, her narrative shifted from that topic to her other physical illnesses. Janet experienced heart failure as a profound loss but also, similar to the integrated narratives, an event that was minimized by her as one among many such losses. Janet summarized her diagnosis by saying, "So that's annoying, and spiritually it just brings you down again." Janet used the understatement "that's annoying," in a way that recalls Bill's perspective-taking. But for Janet, the overwhelming

nature of heart failure plus other illnesses was the basis for spiritual despair rather than gratitude.

Janet's spiritually disintegrative narrative of spiritual coping in heart failure was a story of not-coping and in this her story contrasted with the spiritually transformative and integrative narratives. Unlike the events and experiences that made up the other two plots, Janet's recounted experiences fed into loss: loss of meaning, connection, purposeful existence, and ability to see beauty and goodness in the world. When I asked Janet what gave her meaning or purpose, she was unable to identify anything in the positive but described the inverse: what it was like when she felt a lack of peace:

> "On those days I just stay in bed. [I am] mean to people. [I'm] not meaning to be [mean], but [I'm] just – just fed up. [I'm] stuck in this bed and I can't do anything. I think it's just boohoo for Janet. I don't want to deal with it anymore – done with it. This sucks! Why me? Why do I have to have all [these things] wrong [with me]? Everything's incurable."

Janet's sentiments also show that, unlike other participants, Janet found no reprieve from her suffering in an other-oriented ethic. In fact, the only other-awareness Janet described is an objectification of herself ("boohoo for Janet") that kept her attention trained on her own experiences of brokenness and loss. Janet thus did not express the kinds of connections that would allow her to pass on a legacy of life lessons learned. Janet described her closest connection with her sister saying, "She's in a bubble now. She won't come out of her house. She doesn't go outside. She won't let anybody in her house. She won't get out of her car. All I have her is on the phone, and I miss that a lot because [my phone doesn't work]." While Janet did allude to the idea of God as potentially a benevolent higher power, there was

uncertainty about that God: “I was always told that God won't give you any more than you can handle, but I'm not so sure.” Different from many of the narrators in the spiritually transformative or integrative plots, Janet did not mention hope for a better place after death founded on a benevolent provider conception.

Janet’s interview ended with a story that structurally and thematically echoed her overall narrative: a seemingly random crisis that developed and deepened and lacked resolution, instead cascading into additional problems:

> I can't quite get used to not having the landline, because I hate these phones. I can't operate them. I did get [a cell phone] from the government and nobody could figure it out. It came with no instructions, no book that tells you what this is for. My family, my son is especially good with them, and my nephew's daughter. She showed me how to do things. But let's see, I lost that one. So, my sister bought me a track phone. It was okay, but it didn't work very well. For some reason it would go on mute or vibrate, [but] it wouldn't ring. So, that would make me mad. I flipped it back and broke off the top part. It didn’t completely break off; it was still connected. It worked for a while, but then I guess it got tired of working and [quit] completely. The top part where you see what you're doing quit. I could dial numbers to call people. It did that twice I think and then it – I would call somebody, and I couldn't hear them answer, so it must have been on mute. Since the light wouldn’t come on, I couldn't fix it. Nothing worked. So, how could you have a spirit of anything besides gloom and doom?

Janet’s account of the phones provided an apt capstone for the more extended story of her spiritual life in heart failure. She began by describing a phone no one could operate. The

object, inscrutable to her, came with no instructions. Once she understood how to use it, it was lost. The second phone was even more of a mystery and source of frustration, with parts that failed to work or soon broke. The phones were emblematic of the general sense of lost purpose, meaning, and – literally – connection in Janet's experience.

Janet remained, throughout her interview, in a disorienting crisis that was similar to what other participants described as part of their transformative narratives, but without a turning point or a helper or guide to redirect or point the way to spiritual resources needed to gain her spiritual footing. The narrative Janet told arrived at no peace, or transformation, no affirmation of meaning or purpose. In Janet's account joy, gratitude, meaning, and purpose are missing; there are no guard rails keeping life experiences orderly as demonstrated through the rambling structure of the interview as a whole. Janet's outcome was not peace but "gloom and doom," or rather no outcome at all but being stuck in a cyclical deterioration of health and spiritual distress.

Synthesis: A Model of Spiritual Coping in Terminal Heart Failure

The individual narratives of spiritual coping clustered around three plot structures, which together suggested a preliminary theory of spiritual coping in terminal heart failure. This theory delineates the potential spiritual coping trajectories that a person might take after a heart failure diagnosis and that lead to outcomes of either adaptive spiritual coping or maladaptive spiritual coping. The key concepts of the theory are *formative experiences*, *existing spiritual beliefs*, *heart failure diagnosis interpretation*, *helper or guide, adaptive spiritual coping, maladaptive spiritual coping, spiritual wellbeing,* and *spiritual distress*. Most of the concepts were present in all three plots, though they took different forms. The exception was the *helper or guide*, which was a concept that appeared explicitly only in the

transformational plot but that could have a useful interventional role to play in the spiritually disintegrative trajectory and a supportive role in the spiritually integrative trajectory.

Conceptual Definitions

At the outset, patients have a pre-existing context before heart failure that is represented in this theory by their formative experiences and existing spiritual beliefs. *Formative experiences* were events and responses to those events in the narrator's past that influenced their spiritual formation before their heart failure diagnosis. These are the events that provide context for the existing spiritual beliefs that narrators brought into their heart failure diagnosis experience. *Existing spiritual beliefs* represent the immediate contextual spiritual beliefs that participants drew from at the time of diagnosis. These existing beliefs were an influence in their appraisal and interpretation of the diagnosis. Narrators in this study tended to bring, either explicitly or implicitly, Judeo-Christian beliefs into this appraisal and interpretation process though the strength and details of those existing beliefs varied. Many other existing beliefs might serve as a contextual lens through which a heart failure diagnosis is interpreted. Non-spirituality or the denial of a spiritual domain of human existence might be the existing belief about spirituality. Even the denial of a thing's existence is a belief about that thing that undoubtedly influences the lens through which a person interprets their reality.

Within the context of existing spiritual beliefs, patients are met with a heart failure diagnosis which they interpret in one of two ways. Their *heart failure diagnosis interpretation* is either that the disease represents a manageable situation that is relatively inconsequential and able to be integrated into life, or it is a disorienting crisis that they do not have the resources to manage.

It is this interpretation that sets the course for one of the three spiritual coping trajectories; spiritually integrative, transformative, or disintegrative. Those three spiritual coping trajectories lead to one of two patterns of spiritual coping; maladaptive or adaptive spiritual coping. *Maladaptive coping* occurs within the spiritually disintegrative trajectory in which the patient focuses primarily on loss (meaning, purpose, and connection) and is not able to transcend the illness. These losses lead to a sense of spiritual distress or lack of peace. *Adaptive coping* is present in both the spiritually integrative and transformative trajectories in which patients were able to develop some meaning for their illness (often seeing it as preparation for helping others), maintain a sense of purpose (usually through giving, and gratitude), strengthen connections, and transcend their immediate challenges. The *helper or guide* is a critical influencing component in the transformative pathway that can be a person, event, or thing that reorients the patient to new forms of spirituality that are more suited to addressing the challenges of heart failure. Through the reorientation and spiritual transformation initiated by the helper or guide, the patient who starts by interpreting heart failure as a disorienting crisis can move into adaptive spiritual coping patterns and achieve spiritual wellbeing.

The spiritual outcome of spiritual coping that follows these spiritual coping trajectories is either spiritual wellbeing or spiritual distress. This adaptive coping led to s*piritual wellbeing* which is the positive state of spiritual affairs that in this study was often described by narrators as a sense of peace. Maladaptive spiritual coping led is *spiritual distress* on the opposite end of the spectrum which narrators framed as a lack of peace and implied constituted a state of spiritual disorganization, disruption, or despair.

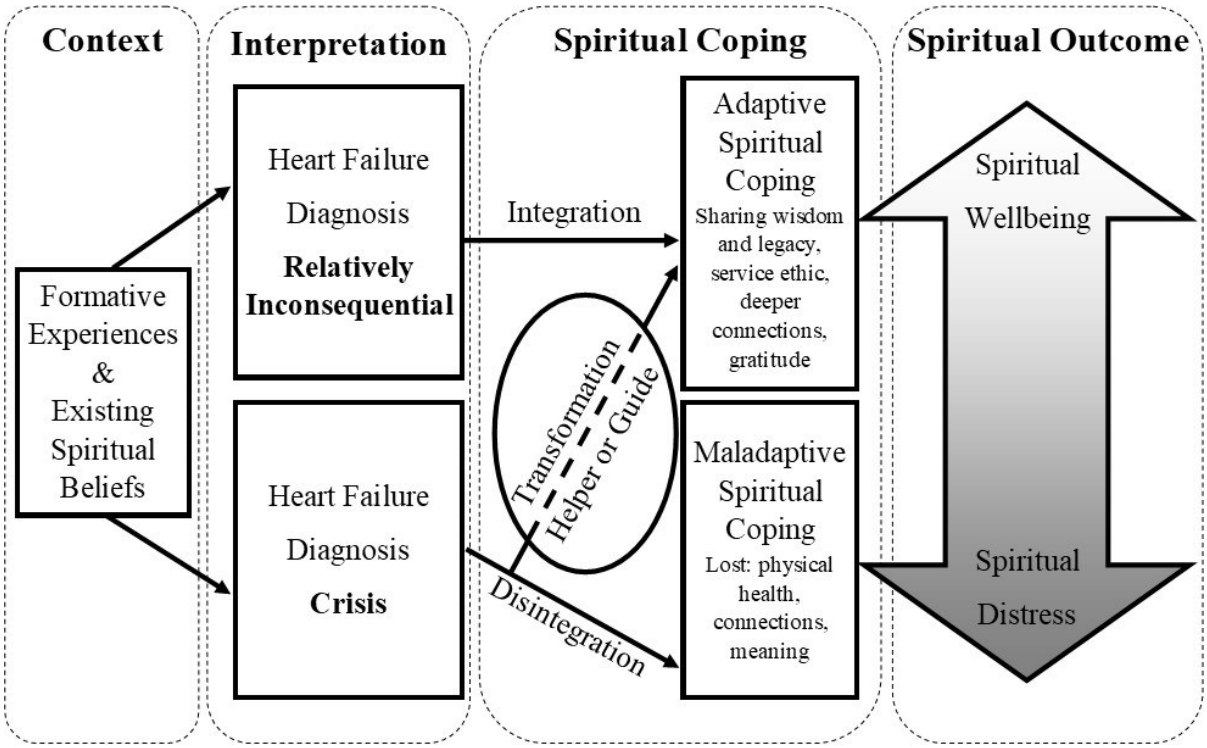
Relational Propositions

Relationships between the concepts make up the main propositions of the theory of spiritual coping in heart failure and include:

1. Formative experiences contribute to spiritual beliefs.
2. Existing spiritual beliefs (which may also be represented in the rejection of spirituality) provide the context in which a heart failure diagnosis is received.
3. The heart failure diagnosis is interpreted as either a disorienting crisis or a manageable challenge.
4. In the spiritually integrative pathway, the heart failure diagnosis is interpreted as a manageable challenge and facilitates integrative spiritual coping moving forward from diagnosis.
5. Interpretation of the diagnosis as a disorienting crisis may lead to transformative spiritual coping or disintegrative spiritual coping.
6. Transformative spiritual coping is facilitated through the influence of a helper or guide which reorients the person toward adaptive spiritual coping patterns versus maladaptive spiritual coping patterns.
7. Integrative and transformative spiritual coping led to spiritual wellbeing (sense of peace) facilitated by adaptive spiritual coping patterns.
8. Disintegrative spiritual coping led to spiritual distress (a sense of a lack of peace) through maladaptive spiritual coping patterns.
9. Spiritual wellbeing exists on a spectrum of wellness to distress. Both dichotomous ends of this spectrum encompass the person's sense of meaning, purpose, connection, and transcendence.

The spiritual coping outcomes were classified as either adaptive or maladaptive. Spiritually integrative or transformative trajectories represented adaptive coping which led to spiritual wellbeing described as a sense of peace. The spiritually disintegrative trajectory might be described as maladaptive coping which led to spiritual distress or a lack of peace. While the narratives analyzed for this study seemed to point to only two outcomes, it is possible that a third outcome of ambivalence might occur. Additionally, this model may not account for the experience of those who simply do not endorse a spiritual component in their lives. Figure 5 presents the synthesized model.

Figure 5
Model of Spiritual Coping in Terminal Heart Failure



Discussion

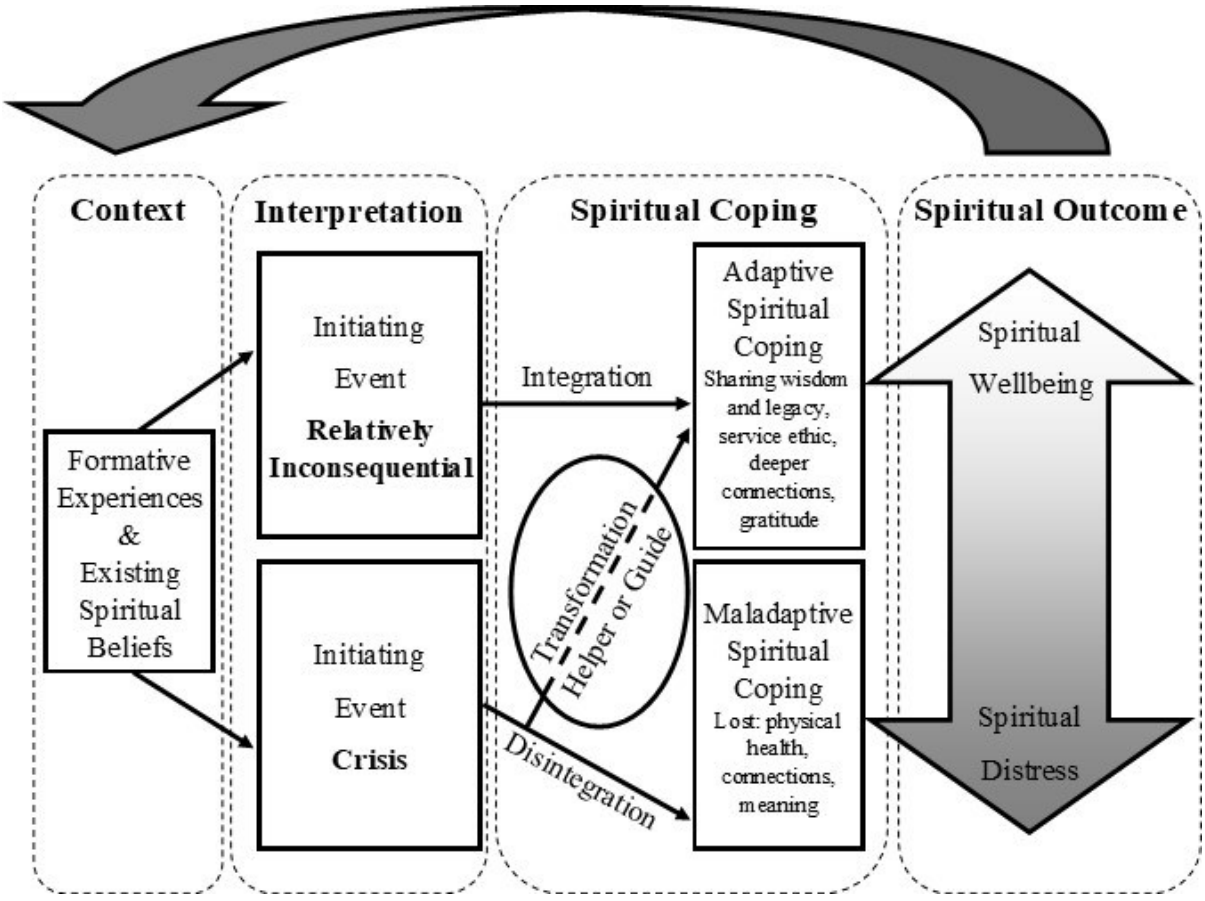
This narrative inquiry derived a new theory of spiritual coping in terminal heart failure from interviews with patients who were asked to narrate their spiritual life before and after their diagnosis. Three trajectories for spiritual coping in heart failure were identified: spiritually transformative, integrative, and disintegrative. Each plot or pathway led to adaptive or maladaptive spiritual coping signified by patients' finding either peace or despair in living with their illness. The theory synthesized from the narratives contributes to our understanding of spirituality while living with terminal heart failure, an understudied aspect of patients' wellbeing and coping.

The primary finding in this study was that while persons experiencing terminal heart failure had individual, diverse experiences of spiritual coping, those experiences could be grouped into three distinctive though sometimes overlapping pathways or plotlines, each with its own thematic emphases. Importantly, all three plots demonstrated a dynamic quality, in which spiritual belief was evolving and influencing the experience of illness, which in turn changed over time and influenced the experience of spirituality. The dynamic interaction was evidenced in all three, though perhaps least so in the spiritually disintegrative pathway.

All three plots, in their dynamism, were evidence of the unique relationship between spiritual coping and terminal heart failure itself, the way coping is fitted to an undulating and cyclical experience of disease that does not end in healing (Murray et al., 2007). Diagnosis with heart failure represented in most cases an initial dual crisis of health and spirituality, more or less momentous, that was followed by a series of subsequent crises, acute exacerbation, hospitalizations, losses of function, and near-mortality experiences, all interspersed with minor easements or palliations. The cyclical but progressive disease burden presented challenges to patients' spiritual beliefs and practices, which in some cases evolved in response. The narratives of this study represent a point in time and questions were structured in a way that caused participants to focus on their diagnosis as a particularly important event. Therefore, the heart failure diagnosis is represented in the synthesized model of spiritual coping in heart failure as a critical point requiring interpretation. Though, by way of theoretical extrapolation, the model synthesized from this study's narratives and represented in Figure 5 might be modified to include a repetitive or cyclical process (Figure 6). In this more dynamic model, the heart failure diagnosis is replaced by any initiating event such as a sudden hospitalization, acute exacerbation, loss of physical function, or near-

mortality experience. This initiating event might trigger the same kind of interpretation as either relatively inconsequential or a disorienting crisis then follow the same adaptive or maladaptive pathways described by this study's narrators. Additionally, the dynamic model in Figure 6 includes an arrow from the spiritual outcome back to the context section of the model at the beginning of the process. This is meant to represent the idea that spiritual wellbeing or distress is not a stagnate state. The spiritual outcome and previous experiences are once again incorporated into a patient's existing spiritual beliefs that serve as the context for any future initiating events. This more dynamic model may serve to sensitize health care providers to the view that spiritual crises may happen for patients at diagnosis but also repetitively throughout the illness. Being sensitive to the potential for repetitive crises, health care providers could engage in ongoing spiritual assessment looking for signs that patients have started down the disintegrative pathway and may require intervention.

Figure 6.
Dynamic Model of Spiritual Coping in Terminal Heart Failure



That spiritual coping both responded to and influenced the experience of living in terminal heart failure accorded with findings in research with patients experiencing other serious illnesses, such as those with cancer and those with chronic pain (Lovell et al., 2021). For the transformative narrators especially, the interactive, dynamic relationship between spirituality and illness was prominent and salutary. Others have observed spiritually transformative patterns in heart failure patients that led similarly to good effects, including Moshki et al. (2020) who found that heart failure outpatients who experienced spiritual transformation had increased appreciation for life, more positive reappraisal of life and

priorities, and improved endurance under stress. Other studies have demonstrated serious heart failure as a transformative or reinforcing spiritual experience that moved patients to become stronger, more accepting, hopeful, and connected, all of which facilitated a more loving and caring relationship with others including caregivers (Penman, 2021). The spiritually disintegrative trajectory observed in this study has also been captured in research including Murray, et al.'s (2007) showing that those with heart failure tended to experience declining spiritual wellbeing over time.

The theory of spiritual coping in heart failure postulates that the way one interprets the heart failure diagnosis is partly a function of one's existing spiritual readiness and orientation. For the spiritually integrative narrators, having a strong sense of spiritual support initially meant being ready to accommodate the shocks of heart failure and seeing them as part of a bigger story. For the transformative narrators, their existing spiritual orientation influenced their interpretation of heart failure as a disorienting crisis. But, being spiritually reoriented through the intervention of a helper or guide toward openness, change, and gratitude meant gaining new ways to meet the challenges of serious illness. Spiritual openness and readiness coordinate well with assumptions that underlie other theories, including the theory of stress, appraisal, and coping (Folkman & Lazarus, 1984). Folkman and Lazarus's focus is broader, describing how coping in general works, the theory of spiritual coping in heart failure shares with that approach an emphasis on the key role of appraisal, the importance of how events are appraised irrespective of their "true" nature, and how responses lead either to further stress or its alleviation (Folkman & Lazarus, 1984). However, Folkman and Lazarus leave out some of the dynamism of coping that the theory of spiritual coping in heart failure captures. In the theory of stress, appraisal, and coping there is

no clear mechanism for moving from the maladaptive to adaptive coping pathway, whereas, the theory of spiritual coping in heart failure describes how spiritual reorientation through a helper or guide facilitates movement of the individual from the maladaptive coping pathway and to an adaptive pathway.

In research with community-dwelling elders, Harris et al. (2013) used the theory of stress, appraisal, and coping to explain relationships between terminal illness and the quest for life meaning/purpose. Harris et al. found that, while illness was often viewed as a challenge, a sense of meaning was achieved, similar to what I found, through belief in a higher power, purposeful connections, and gratitude. Harris et al. discerned the adaptive spiritually integrative and transformative plots but did not observe how patients interpret major stressors diversely, in some cases as harmful and debilitating while in others as an opportunity for growth. In this study, the appraisal of an initiating event as a threat or opportunity pointed the way to adaptive or maladaptive spiritual coping.

The theory of spiritual coping in heart failure differs from previous theories, including Folkman and Lazarus's in its specificity to heart failure as a stressor, its view of spirituality as a coping mechanism, and in its inclusion of the failure to cope. The theory of stress, appraisal, and coping does not provide specificity about how people with heart failure use spirituality to adapt in the face of the dynamic heart failure stressor. In contrast, the three pathways of the theory of spiritual coping in heart failure offer specific ways to understand that coping, e.g., meaning through a higher power or philosophy, connections for legacy and sharing wisdom, a service ethic, and experiencing gratitude. This more grounded understanding of the spiritual coping processes in heart failure opens possibilities for targeted future exploration and intervention.

Also important to the theory is its inclusion of a spiritually disintegrative plot or maladaptive pathway. Folkman and Lazarus (1984) suggest that stress occurs and continues because a person initially judges that they are not able to respond to a stressor. The theory of stress, appraisal, and coping does not account for the development of spiritual distress or despair as was described by the participant, Janet. By acknowledging the spiritually disintegrative plot, with its dominating interpretive lens of loss, practitioners will be better able to guide patients in identifying areas of loss and either reinterpreting these or developing strategies to minimize them. In Folkman and Lazarus's theory, there is no defined role for the practitioner. Finally, Folkman and Lazarus provide a process model that describes a predominantly internal process of patient coping without a clear opportunity for practitioners to intervene. The model of spiritual coping in heart failure postulates that a practitioner can function in the helper or guide role and how that might be accomplished. This will be foundational in the future development of nursing interventions.

The contribution of this work to research on spiritual coping in heart failure lies in the three plots which map coping processes by which a person reaches spiritual wellbeing or distress in the specific context of heart failure. Previous literature focused primarily on discovering what characteristics (i.e., having existing spiritual beliefs or tending toward a particular interpretive paradigm regarding challenges) were correlated with spiritual wellbeing (Clark & Hunter, 2018), but lacked an explanatory mechanism. The theory of spiritual coping in heart failure offers relational propositions to explain how stable spiritual beliefs lead to spiritual wellbeing or its absence. In this way, the theory helps us understand how participant characteristics link to their spiritual state.

Moreover, the specific spiritual coping features of the plots, such as other-oriented service and a focus on gratitude, provide a foundation for developing interventions to facilitate adaptive spiritual coping among patients with heart failure. The helper or guide role, in particular, suggests the function a nurse or other health care provider might play within the spiritual coping process. This helper or guide role should be explored further through qualitative methods and should include analysis to detect provider characteristics and strategies that lead to adaptive spiritual coping. The model of spiritual coping in terminal heart failure introduces specificity to our understanding of adaptive and maladaptive strategies framed within defined plot trajectories and the role of the provider that neither spirituality theory nor coping theories provide.

Clinical and Research Implications

Theoretical specificity improves clinicians' abilities to develop empathy, assess patient status, and provide anticipatory guidance and coaching (Kearney, 2001). The model synthesized in this study provides a basis for practice change, particularly for nurses who could perform the function of helper or guide for patients within the spiritually disintegrative pathway to cultivate resources to move into the transformative pathway. For those in the spiritually integrative pathway, nurses using the model of spiritual coping in terminal heart failure could support patients' existing spiritual frameworks by facilitating opportunities to foster and share their healthy and adaptive coping with others.

Future research is justified to develop the model, codify the relationships it proposes, and test the strength and potential mediators of those relationships. Replicating this study with a different, more diverse sample would help strengthen and clarify the theoretical model. Subsequent work based on the findings could include the development of instruments

to measure spiritual coping, assessment tools for clinical practice, and interventions to identify threats to healthy spiritual coping in heart failure and to promote practices that enhance spiritual coping. Palliative care practice within the spiritual domain may benefit from improved standards of care and the integration of interventions developed from the model of spiritual coping in heart failure.

Limitations

This study developed a typology of narrative pathways based on in-depth interviews with 10 patients with terminal heart failure. The identification of pathways may be incomplete or limited in three ways. First, the small number of participants, their single geographic location, and their largely homogenous racial and spiritual/religious profiles (i.e., white and Protestant) may mean that there are other narrative types that I missed. Second, there is also a risk that my interpretation of the narratives was biased by my own religious and sociocultural background. I implemented practices to minimize that bias and enhance the trustworthiness of the results by identifying my position in the research, memoing reflexively during the study, using second-reader verification, and presenting ample narrative quotations to support my interpretations. Nevertheless, replication of this study by or in collaboration with other investigators and a more racially and socio-culturally diverse sample from different geographical settings would help increase the trustworthiness of the results and the applicability of the theory that was synthesized from them. A third limitation of the study arose with the COVID-19 pandemic, which affected the data collection and may have introduced unique challenges to the spirituality, coping processes, and psychology of participants or may have affected their outlook. Though some participants did talk about COVID-related distress, this was not a major focus of the interviews.

Conclusion

Using narrative inquiry, I identified three plots or trajectories for spiritual coping and characteristic themes: heart failure as spiritually transformative, integrative, or disintegrative. The three trajectories were synthesized into a model of spiritual coping in terminal heart failure that describes both adaptive and maladaptive spiritual coping pathways and strategies. The study fills a gap in the existing literature by offering a disease-specific model that can be used to support further research, including theory testing and intervention development to improve spiritual coping in those with terminal heart failure. Filling this gap aids researchers and clinicians in relieving the burden of suffering experienced by those with heart failure. Relieving spiritual suffering is part of a multi-dimensional approach to treating heart failure, an approach that could reduce suffering, improve quality of life, and have social and systemic benefits, including health care savings.

CHAPTER 5

DISCUSSION

This narrative inquiry aimed to describe the spiritual coping experiences of individuals with terminal heart failure and synthesize a model of spiritual coping specific to the disease. I found that the narratives of those with terminal heart failure clustered in three plots: heart failure as spiritually transformative, integrative, or disintegrative. The particularities of the plots and the embedded themes add to our understanding of spiritual coping in heart failure by providing specificity about how the particular crisis of heart failure is experienced and by illuminating the strategies that patients develop to cope with the illness. This work, similar to other research on spirituality in illness, highlights distinctions between spirituality and religion and the intertwined, holistic nature of fluctuations in physical, mental, and spiritual wellbeing. The theory of spiritual coping in heart failure contributes to the science in its specificity to heart failure, a unique disease with a cruelly fluctuating, progressively declining course. The model points the way to future research and ultimately the development of guidelines for practicing nurses so they can recognize spiritual coping processes in patients with heart failure, anticipate needs, and provide guidance and support.

Spiritual Coping in Heart Failure: Three Variations

The key finding in this study was that the narratives of spiritual coping in patients followed three patterns. Murray et al. (2007) describe those with cancer and heart failure as having only declining spiritual wellbeing, tied to particular crisis points in their illness. This study shows that spiritual wellbeing in heart failure can remain intact and a valuable tool for coping with the challenges of the illness. Most patients find their spirituality challenged by

the crisis of a heart failure diagnosis. What this study illuminated were some of the spiritual coping pathways that patients took either to integrate or transform their outlooks and gain hope. It is possible that patients with cancer would cope similarly, though that might look different given what researchers have found to be the rather different trajectory of spiritual decline noted in patients with terminal cancer (Murray, et al. 2007). The opportunity for spiritual transformation highlights a potential window for nursing intervention with heart failure that is not presented in other research on spirituality in terminal illness.

Spiritual Wellbeing

This study contributes to the literature by providing an explanatory model for the connections between the interpretation of the physical illness and spiritual wellbeing that have been observed in other studies (H. Y. L. Chan et al., 2016). Chan et al. found that quality of life was determined by a tight correlative interplay between existential, physical, and psychological wellbeing. This fits with the three-plot variant in the theory of spiritual coping in heart failure – especially the spiritually integrative and transformative plots. When narrators interpreted or were reoriented toward a spirituality that was adaptive and functional for managing the illness, the outcome was spiritual wellbeing and peace regardless of the severity of their illness.

In contrast, when Janet, who narrated the spiritually disintegrative plot, met the crisis of diagnosis and subsequent deteriorations in health, she displayed a maladaptive spiritual coping that was not effective in managing the challenges of heart failure, and the outcome was spiritual distress, loss, and a lack of peace (which she sometimes described as depression). In times of crisis, including the crisis of terminal illness itself, persons may find it difficult to assign meaning or purpose to events (Lee, 2020). Connections can be disrupted

due to symptoms, hospitalization, and loss of function (Lee, 2020). Meaning and connection are fundamental components of spiritual well-being that, according to Murray et al. (2007), are closely tied to the fluctuation of physical symptoms in those with heart failure. As those with heart failure experience increases in symptom burden, their spiritual wellbeing tends to decline. Murray et al. (2007) demonstrated that diagnosis may represent a spiritual crisis but even fluctuations in symptom burden can be interpreted as crisis moments for those with heart failure. In this study, the narrators discussed both the potential crisis of diagnosis but also the repetitive challenges they faced with day-to-day fluctuations in health. The difference in spiritual wellbeing outcomes between the plots was based on the interpretation of the diagnosis and daily challenges. Based on the narrated experiences in this study, crises and challenges may trigger a spiritual decline resulting in further distress as described by Murray et al. but may also trigger adaptive spiritual coping leading to peace (spiritual wellbeing). The greater number of narrators falling into the spiritually integrative and transformative plot categories versus the spiritually disintegrative plot provides an interesting contrast to the statistical findings from the larger sample examined by Murray et al. in which most patients with heart failure experienced spiritual declines along with illness challenges rather than maintenance of spiritual wellbeing.

Others have documented how mental health, especially depression, is a common correlate of spiritual wellbeing (Anyfantakis et al., 2015; H. Y. L. Chan et al., 2016; Mills, et al., 2015). Each of these studies demonstrated that poorer spiritual wellbeing translated into more severe depression. In this study, Janet tied her spiritual state directly to her feelings of depression. Other participants noted how sadness, anxiety, and a sense that they had lost control affected their experiences of spirituality and illness. There are measurement

difficulties in distinguishing depression from spiritual wellbeing due to conceptual overlap (Garssen & Visser, 2016). Janet's narrated experience displayed this relationship since she made little distinction between her depression and spirituality.

In many respects, the current study is congruent with other research, but in offering a model to explain how some people maintain or improve their spiritual wellbeing during illness the research adds to our understanding that spiritual coping may follow at least three variations in trajectory. The model of spiritual coping in heart failure puts the patient's interpretation of stressful events at the root of that variation. However, the interpretation is not fixed, as demonstrated by the transformative plot. It is possible for patients to have their interpretive lens reoriented toward spiritual coping that is more adaptive than maladaptive through the intervention of a helper or guide. The interpretation of the stresses of heart failure is then tied to particular spiritual coping patterns that ultimately influence the patient's spiritual wellbeing.

Theoretical Convergence and Contributions

The theoretical framework developed in this study demonstrates convergence with the theory of stress, appraisal, and coping (Folkman & Lazarus, 1984). Each of the three plots demonstrates appraisal related to the heart failure diagnosis. After this appraisal, the event is interpreted as either inconsequential or a threat (Folkman & Lazarus, 1984). The sequence of appraisal and interpretation described by Folkman and Lazarus follows the same trajectory present in the narrators' plots in this study. Folkman and Lazarus (1984) would also suggest that those who interpreted the heart failure diagnosis and disease process as a threat can then further interpret, based on their available resources, the event as a growth opportunity or as overwhelming. Again, the assessment of resources and the determination of the event as a

growth opportunity or as overwhelming follows the spiritually transformative or disintegrative plots in heart failure. The convergence of the spiritual coping model in terminal heart failure with the theory of stress, appraisal, and coping demonstrates a clear connection between our current understanding of generalized coping and the narrators' experiences related through the spiritually integrative, transformative, or disintegrative plots. The benefit of the model of spiritual coping in terminal heart failure is that it describes specific adaptive and maladaptive coping patterns described by the narrators. Coping patterns such as focusing on gratitude, an other-oriented ethic, and maintaining connection were adaptive. Maladaptive coping patterns included a negative focus, uncertainty about the benevolence of their higher power, and disrupted connections were maladaptive coping patterns. By understanding adaptive and maladaptive coping patterns specific to spirituality in heart failure, and with the addition of the helper or guide role, the model of spiritual coping in heart failure points the way to more practical applications than the more abstract stress, appraisal, and coping theory.

In Chapter 2, I defined spiritual coping as the cognitive and behavioral efforts derived from a personally meaningful spiritual framework employed in response to life stressors. In the case of narrated experiences reported in Chapter 4, that initiating stressor was heart failure. Some participants interpreted the stressor as non-threatening while others interpreted it as a disorienting crisis. Regardless, all participants engaged in some spiritual or religious coping patterns. These patterns were either adaptive or maladaptive. The interpretation and subsequent adaptive or maladaptive trajectory fits with the process model outlined in the spiritual coping concept analysis (Figure 1, p. 17). The benefit of the three-pathway model in this study is that in reflecting a diversity of experiences, the model captures some of the

nuances in the process of coping. Those nuances are present in the variability in which participants interpreted heart failure. Additionally, the theory of spiritual coping in heart failure specifies the coping patterns they used to attempt to manage the illness experience.

The theoretical convergence between the theory developed in this study and the existing theory of stress appraisal and coping as well as the theoretical model described in Chapter 2 from the concept analysis tends to validate the results of this narrative inquiry and substantiates the theoretical claims made. This convergence is expected since coping processes and spirituality were the major topics of interest in the current study. However, the unique features and focus of the theory generated by this narrative inquiry clarified concepts and processes that are more abstract in other theories and in that way, points to practical applications.

Research Implications

Future research should focus on model testing and refinement as well as spiritual coping intervention development. Model testing might use quantitative designs to examine relationships between connection, gratitude, altruism, and spiritual wellbeing in patients with terminal heart failure that appeared as coping mechanisms or factors in each of the three plots. First, the major concepts and themes in this narrative inquiry should be operationalized. That would include developing an instrument to measure the participant's pre-existing spiritual beliefs, their interpretation of the heart failure diagnosis, their identification with features of one of the three plots, and the degree to which the participant has adopted adaptive or maladaptive coping patterns. Once this instrument is developed, factor analysis might be used to examine whether or not the instrument is valid. Additional psychometrics research would need to be done to show the instrument as valid and reliable.

Next, it would be useful to test the relationships between the major pathway categories and the predicted outcomes. For example, a person's identification with one of the plots (spiritually integrative, transformative, or disintegrative), in addition to measures of spiritual wellbeing, could be included as variables within a cross-sectional correlative design or used in a path-analysis design for theory testing. If this sort of testing showed that participants who identified with the spiritually integrative or transformative trajectory were more likely to have greater spiritual wellbeing than those who identified with the spiritually disintegrative trajectory, this would provide some validation of the model of spiritual coping in terminal heart failure.

Once these major relationships are tested between the pathway trajectories and the major outcome of spiritual wellbeing, the coping patterns identified as themes (i.e., connection, gratitude, altruism, etc.) in each of the coping pathways could be examined as mediating variables. An instrument might include questions aimed at assessing the frequency or quality of adaptive or maladaptive spiritual coping attitudes or mechanisms based on this study's findings. The COPE inventory (Carver et al., 1989) does this, but on a more general level, as it is based on the theory of stress, appraisal, and coping. An instrument based on the model of spiritual coping in terminal heart failure would have specificity for spiritual cognitive and behavioral coping associated with the particular stresses of heart failure rather than general stress and a multiplicity of coping approaches.

Intervention development might utilize the model of spiritual coping in terminal heart failure to create a program that can be administered by bedside nurses in a brief, patient-driven format. Brief interventions of this nature are effectively used in mental health settings for screening, increasing motivation to change, and determining the need for referral to more

extended interventions (Agerwala & McCance-Katz, 2012). Similarly, advanced care planning is routinely completed with episodic discussions between nurse and patient and a worksheet type document used to guide the patient, mostly independently, through the process (Schrijvers, & Cherny, 2014). Such an intervention would facilitate spiritual coping by helping patients develop positive coping based on spiritually integrative and transformative pathways. These might include activities to practice gratitude, identify or cultivate connections, and explore opportunities for legacy and altruistic service. For example, a workbook of questions and planning exercises and brief counseling sessions to discuss with a nurse or chaplain might help the patient to identify personally meaningful spiritual practices. Research might explore the differential effects of such an intervention on patients in the three pathways. Movement from a less to a more adaptive pathway could improve spiritual wellbeing. As previous research on spirituality and health has demonstrated, overall health and quality of life might also improve by affecting the mental and physical components correlated with spiritual wellbeing (Clark & Hunter, 2019).

Clinical Implications

Situated or contextual theories like the one developed in this study provide the most utility for clinical application (Finfgeld-Connett, 2018a) compared to more abstract and higher-level theories. One way to go about applying the model of spiritual coping in terminal heart failure might be for practicing nurses to implement knowledge of the spiritual coping pathways in heart failure using Kearney's (2001) categories of clinical application of qualitative research. These include cultivating empathy, assessing status or progress, providing anticipatory guidance, and facilitating coaching.

Empathy in nursing practice is correlated with improved ethical practice as well as improved quality of care (Teófilo et al., 2019). Descriptive qualitative research is conducted to understand patient perspectives and can provide a basis for nurses to develop an empathic understanding for patients (Kearney, 2001). Through this study, nurses are provided an opportunity, via the narrative segments, to take the perspective of patients with heart failure. Research suggests that narrative or literary works have a strong effect on perspective-taking, which is a central component to empathic understanding (Kidd & Castano, 2013). Therefore, reading qualitative research with significant narrative segments, like this one, could be especially useful in helping nurses to cultivate empathy for their patients. Additionally, workshops with vignettes or narrative-based interventions based on the pathways might be used to disseminate the theory and train practitioners to interpret and respond to patients' coping. Narrative segments about experiencing heart failure as a kind of crisis or loss might be especially helpful for nurses as they seek to act compassionately. Crises and the resulting stress represent a tremendous burden for patients that must be calculated into the ethical decision-making undertaken by clinicians, especially in terminal conditions (Fleming, 2005). The expression of empathy can also facilitate the development of the therapeutic nurse-patient relationship.

Spiritual assessment and diagnosis are important components of holistic nursing practice (American Nurses Association, 2015). The model of spiritual coping in terminal heart failure could provide health practitioners with a structure for understanding the process of coping experienced by patients diagnosed with heart failure. By assessing the patient through the lens of the model of spiritual coping in terminal heart failure, health practitioners can place their patients within the process and develop appropriate diagnoses.

Knowledge of the theory of spiritual coping could enable practitioners to better understand where the particular patient needs help by indicating what kind of trajectory they are following and thus what might lie ahead (Kearney, 2001). Anticipatory guidance might be especially helpful to patients who are interpreting heart failure as a kind of crisis. Based on the model, this interpretation of heart failure can potentially lead to a spiritually transformative or disintegrative experience. If health providers can help patients recognize these two potential pathways and their outcomes, it can motivate movement toward the spiritually transformative rather than disintegrative pathway.

Coaching is a more actively interventionalist approach by the health providers to help patients set goals and develop plans to facilitate recovery or management of health. Healthcare providers might offer specific strategies or approaches based on research to help patients reduce stress or improve adjustment to a health condition or experience (Kearney, 2001). The theory could be used to guide patients' adjustment to the diagnosis of heart failure in any of the three plot categories, including strategies to develop or maintain connections, gratitude, legacy, and other-oriented service. With coaching, patients with heart failure might strengthen their approaches to coping in ways that promote peace and spiritual wellbeing.

Limitations

This narrative inquiry was conducted with a small sample to develop a model that will require testing. As with all qualitative research, it is possible that findings in this study are partial, that some experiences have been missed that interviews with a larger, more diverse group would have revealed. I used a purposive sampling approach that focused on diversity in age, religious orientation, heart failure stage, and time since diagnosis to mitigate this limitation. One benefit of narrative inquiry is that the frequency of an experience is less

important than the depth, detail, and explanatory potential (i.e., participants' assigned meanings) of the descriptions of an experience. A single narrative can be sufficient to illuminate the existence of a thing and provide insight into its shape and meanings. This is less the case in quantitative approaches where singular occurrences are flattened to outlier status or non-significance through statistical procedures.

A second limitation is a potential for interpretive bias. In narrative inquiry, where segments of text or talk are analyzed for meaning, interpretive bias is inevitable. This bias can be managed through study design features that enhance correspondence, coherence, and persuasiveness (Riessman, 2008). I attempted to provide evidence of the correspondence between interpretations and data by including sufficient data in the text to enable readers to judge the trustworthiness of the interpretations I made from the interviews. I used triangulation of analysis through checking and validation by a second reader to further mitigate interpretive bias. Persuasiveness relates to how convincingly links are made between a study's findings and the broader theoretical and research-based claims they are used to support. I worked to enhance persuasiveness in the discussion section by demonstrating how my findings of spiritual coping in heart failure fit within with the broader theory of stress, appraisal, and coping, as well as the many ways the concept has been defined (i.e., Chapter 2).

Another third limitation of this research was that the timing of data collection during COVID-19 might have distorted the participants' views regarding connectivity and perhaps their sense of hope and peace. Participants often discussed changes in their connections, mental health, and experiences on the whole related to the isolation and stress caused by COVID-19 and policy responses to the pandemic. It is possible that the presence of COVID-

19 contributed to poor spiritual wellbeing and represented an additional, extraordinary challenge to participants' spiritual coping. For the most part, my analysis did not address narrative segments that focused on COVID-19, as this was not the primary aim of the study, and those passages were not dominant. The major theme in those segments of text was increased isolation that disrupted the participants' opportunities for connecting with others. The narrators I interviewed lived in a fragile state because of their heart failure, and any major event like COVID-19, could represent a tipping point in that balance. The COVID-19 interview segments deserve their own attention, and I plan to analyze and publish those findings separately.

Conclusions

This narrative inquiry met the intended aim of synthesizing a model of spiritual coping in individuals with terminal heart failure. The spiritual coping process followed three narrative plots, each with its own thematic emphases. While the spiritually integrative and transformative plots resulted in spiritual wellbeing and peace for participants, the spiritually disintegrative plot produced a lack of peace and poor spiritual wellbeing. The model fills a current gap in the literature by improving the specificity of what we understand about spiritual coping in patients with terminal heart failure. Future research to develop this model should test the relationships and refine the themes or mechanisms. The development of an instrument to measure patients' needs congruent with the pathways might enhance our ability to support them. Interventions to promote factors associated with transformation and integration or address disintegration might be developed and tested. As we come to understand more about the pathways and the mechanisms by which they lead to wellbeing or its absence, that understanding might come to inform nursing practice. By applying

Kearney's criteria for the application of qualitative research, the theory of spiritual coping in heart failure could be taught to healthcare providers as a way to develop empathy, structure assessment of spiritual status, shape anticipatory guidance, and provide a basis for facilitative coaching.

An estimated 6 million Americans live with heart failure. For many, spiritual coping means struggling to find meaning, connection, purpose, and transcendence. The model of spiritual coping in terminal heart failure provides specific evidence about three primary ways in which persons with both adaptive and maladaptive coping approaches understand and manage spirituality in the context of serious illness. The model usefully points us in the direction of developing targeted interventions to help healthcare providers deliver better care, improve spiritual wellbeing, alleviate suffering, and decrease healthcare costs within a framework of holistic nursing practice.

APPENDICIES

Appendix A: Citations and Studies Included in Analysis

Citations Included in Review Findings

Citation	Design	Sample	Findings
Alvarez et al. (2016)	Correlational, cross-sectional	Ambulatory clinic, newly diagnosed (n = 130)	Adherence positively correlated with quality of life; spirituality positively correlated with adherence with weak magnitude, spirituality positively correlated with quality of life, and religiosity
Anyfantakis et al. (2015)	Correlational	n=195 Greece	Depression inversely correlated to spirituality, sense of coherence inversely correlated to depression, increased sense of coherence positively correlated with spirituality
Bean, Gibson, Flattery, Duncan, and Hess (2009)	Correlational	n=100, 67% male 1/2 African American, 45% advanced HF	African American's had higher faith scores; avoidant coping negatively correlated with meaning/peace, and quality of life; anxiety negatively correlated with meaning/peace, and positively correlated with approach coping; Spiritual wellbeing positively correlated with quality of life; quality of life mediates the relationship between spiritual wellbeing and depression.
Bekelman et al. (2007)	Cross-sectional, correlational	n=60, ≥60 y.o., NYHA II-IV	Spirituality inversely correlated with depression; only meaning and peace significantly contributed to the effect
Bekelman et al. (2010)	Correlational; instrument comparison	60 outpatients with chronic HF; Baltimore, >60 you,	FACIT-SP meaning/peace subscale modest correlation with IW sense of peace subscale; FACIT-SP faith subscale correlated with all of

			the IW subscales; meaning/peace subscale strongly associated with less depression and greater quality of life. IW is not associated with either depression or QoL except faith in God with quality of life.
Bekelman et al. (2009)	Cross-sectional study; descriptive	60 outpatients with symptomatic heart failure and 30 outpatients with advanced lung or pancreatic cancer (n = 90), mean age of HF subjects 77, of Ca subjects 64. HF 36.7% female, Ca 60% female	Similar number of physical symptoms, depression scores, and spiritual well-being; advanced heart failure > physical symptoms, depression scores, lower spiritual well-being than patients with advanced cancer.
H. Y. L. Chan, Yu, Leung, Chan, and Hui (2016)	Correlational	n=112, >65 y.o., NYHA III or IV, in China	"life is worthwhile item" SIS score (wellbeing) attached to value/meaning, QoL associated with existential wellbeing, psychological wellbeing, and physical wellbeing and educational level
K. Y. Chan, Lau, Cheung, Chang, and Chan (2016)	Case report on effectiveness of Life Review intervention	86 y.o. Chinese woman, NYHA III	Restored hope; greater social participation; physical symptoms improved; depression improved
Chaves and Park (2016)	Correlational, test-retest (6-month interval)	"Small sample size" could not find the n or other descriptive details	Age positively correlated with life satisfaction, spiritual wellbeing, and negative health behavior change; Positive affect and spiritual wellbeing made approach coping more likely; decreased spiritual wellbeing

			led to negative avoidance and increased negative health behavior change.
Griffin et al. (2007)	Correlational, descriptive	>65 y.o., 44 with HF (II-IV) and 40 without	HF patients significantly lower physical quality of life but greater spiritual well-being than non-HF patients
Gusick (2008)	Correlational	Clinic setting, SW U.S., n=105	Depression positively correlated to symptom frequency and intensity; spirituality inversely correlated to depression
Heo, Lennie, Okoli, and Moser (2009)	Qualitative, content analysis	14 men, 6 women, 58 y.o. plus or minus 10 years with heart failure	Defined QoL as ability to perform desired physical and social activities to meet theirs and family needs; maintain happiness; engage in fulfilling relationships; factors that affect these things include physical, psychologic, economic, social, spiritual (faith in God, praying), and behavioral
Hopp, Thornton, Martin, and Zalenski (2012)	Qualitative: Focus group and individual interviews	African American, > 60 y.o., advanced heart failure, Detroit, n = 35	Living scared: anxiety about heart failure, making sense of heart failure: understanding the disease, limiting activities, resiliency, self-care, spirituality: life meaning (not taking things for granted, changing values/priorities, letting things go, gratitude), religious activities; life meaning is an important theme that is consistent with other literature and the consensus definition.
J. O. Johnson, Sulmasy, and Nolan (2007)	Qualitative: descriptive method, content analysis: constant comparison method	3 subjects: AA male lung cancer, AA female HF, C female with ALS	Connection with God and maintaining relationships, assigning cause to the illness, focusing on their remaining abilities and roles and reminiscing about the

			satisfaction with their former roles (tied to the cognitive restructuring involved in meaning-making)
K. S. Johnson et al. (2011)	Cohort, correlational	n=210, 33% Ca, 33% COPD, 33% CHF, mean of 66 y.o., 91% Christian	Beliefs about the role of faith plus meaning/peace/purpose associated with decreased anxiety; greater past negative religious experiences lead to greater anxiety
Lum et al. (2016)	Correlational	VA hospitals, primarily Caucasian men; n=384	Reported feeling a limited sense of peace (6% ‘‘not at all at peace,’’ 17% ‘‘a little at peace’’). In bivariate analyses, the baseline patient-reported factors, including diverse physical symptoms, depressive symptoms, limited sense of peace, and comorbidity count, were correlated with KCCQ score over one year.
Mills et al. (2015)	Correlational	n=186, 66.5 years plus or minus 10 years, asymptomatic stage B	Gratitude positively correlated to better sleep, less depression, less fatigue, better self-efficacy, lower levels of inflammatory markers; spiritual wellbeing positively correlated with sleep, and inversely correlated with depression and fatigue. Mediation analysis: spirituality mediated by gratitude for sleep quality, depression; partially mediates fatigue, self-efficacy. No relationship between spirituality and inflammatory index.
Murray, Kendall, Boyd, Worth, and Benton (2004)	Qualitative	20 cancer patients, 20 NYHA Class IV patients	Whether or not patients and caregivers held religious beliefs, they expressed needs for love, meaning, purpose and sometimes transcendence.

			Patients often looked back at their lives to try to make Sense of why this illness had occurred. The experience of people with heart failure was different, reflecting a different illness trajectory of gradual physical decline punctuated by episodes of acute deterioration. Many heart patients felt abandoned by health and social care services in the community, often believing that professionals thought nothing more could be done for them. Maintain relationships with family, give and receive love, feel connected to social world (religious community also), facilitate hope and positive thinking.
Murray et al. (2007)	Qualitative synthesis of interview data from two separate studies	1. 20 cancer and 20 HF 2. 20 with various illnesses; all in Scotland; 112 interviews with 48 patients	Patients searched for meaning, life purpose, loss of social connection, transcendence (is there a higher power, etc.). Cancer needs increased at transitions of care, HF needs reflected physical deterioration, spiritual distress modulated with perceived lack of understanding of the issues by health providers.
Park et al. (2016)	longitudinal (5 year), correlational	n=191, mostly I to II at baseline	Spiritual peace decreased mortality (social support and religious attendance, not predictors)
Paturzo et al. (2016)	hermeneutic phenomenological	n=30, mostly male, mean age 71, mostly NYHA I or II	Themes: 1) major life changes, 2) social isolation, 3) anger and resignation, 4) relief from spirituality 5) will to live, 6) uncertainty about the future, 7)

			inescapability. Spirituality carried only a religious theme.
Ross and Austin (2015)	Qualitative: narrative analysis	n=16 South Wales	Physical needs, love and belonging, hope (maintaining a fighting spirit), coping, faith/belief, meaning and purpose, existential questions; Needs: home visits (or telephone), care coordinator, volunteers, supporting careers
Sacco, Park, Suresh, and Bliss (2014)	Mixed methods, correlational	111 participants, NYHA III-IV	Social support, religion, and gratitude tied to increased life meaning and QOL, Religion, and spirituality were inversely correlated with death anxiety and depression and positively correlated with life satisfaction.
Steinhauser et al. (2006)	Correlational	n 248, advanced illness including some HF, NC	Significant relationship with single item "Are you at peace?" and faith and purpose subscales of the FACIT-SP, small relationship with QoL, physical well-being, and social support. Appears to effectively capture meaning and purpose but only weakly captures connectedness.
Tadwalkar et al. (2014)	Test-retest at 2 weeks and 3 months for a spiritual care intervention.	CHF for 3 months, NYHA III-IV, n=23?	Positive FACIT-Sp-Ex trend on repeated measures; decreased depression; positive response multi-symptom assessment; improved QoL. Intervention was not well described.
Vollman, LaMontagne, and Wallston (2009)	Correlational	n=75, middle-aged men, protestant, married, half with class III	Increase religious well-being correlates to increased existential wellbeing. Statistically significant association between existential wellbeing and perceived control.

Studies Included in the Thematic Concept Analysis

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Appendix B: Letters of Support

Health Care

Mary S. Beck, DNP, RN, NE-BC
Chief Nursing Officer

1 Hospital Drive, DC031.00
Columbia, Missouri 65212
PHONE: (573) 884-8644
FAX: (573) 884-4174

April 18, 2018

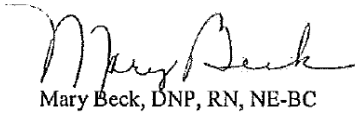
Clayton C. Clark, MSN, RN
Ph.D. Student
University of Missouri-Kansas City
Kansas City, Missouri 64108

Dear Clayton:

I am pleased to offer my support for your dissertation study "A Narrative Analysis of Spiritual Coping in Terminal Heart Failure". As the Chief Nursing Officer at MU Health Care, I fully support this study including assessing potential participants from MU Health Care.

Spirituality is an important aspect of patient care, especially in serious or terminal illness. Your work will add valuable insights and help to facilitate the development of interventions to address spiritual needs and the heart failure population. I look forward to supporting you in your work.

Sincerely,



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April 23, 2019

Clayton C. Clark, MSN, RN
PhD Student
School of Nursing and Health Studies
University of Missouri – Kansas City
Kansas City, Missouri 64108

Dear Mr. Clark,

I am pleased to offer my support for your dissertation study, "A Narrative Analysis of Spiritual Coping in Individuals with Terminal Heart Failure".

As Medical Director of the Inpatient Cardiovascular Service Line, I support this study including accessing potential heart failure participants at MU Health Care, University Hospital (pending approval per hospital policy). This descriptive study is necessary to better understand how spirituality impacts the well-being of our patients with heart failure.

Sincerely,

Arun Kumar
Medical Director, Inpatient Cardiovascular Service Line
University Hospital
MU Health Care

April 16, 2019

Clayton C. Clark, MSN, RN
Ph.D. Student
University of Missouri-Kansas City
Kansas City, Missouri 64108

Dear Clayton:

I am pleased to offer my support for your dissertation study "A Narrative Analysis of Spiritual Coping in Terminal Heart Failure" As Service Line Manager of the Cardiovascular Service Line at University Hospital, MU Health Care, I fully support this study including assessing potential heart failure participants from MU Health Care.

Spiritual coping in advanced heart failure is a critical problem in which new insights are needed to improve patient outcomes and develop future interventions. We look forward to supporting you in your work.

Sincerely,

Melissa Dowler

Melissa Dowler, MSN, RN-BC
Nursing Manager, Inpatient Cardiovascular Service Line
MU Health Care

Appendix C: Demographics Collection Form

Participant ID: _____ Phone Number for interview scheduling: _____
Age:_____Gender: _____

Religious Preference: _____

Frequency of Religious Service Attendance:
☐ At least weekly
☐ At least once per month but not every week
☐ At least once every 6 months but not every month
☐ At least once per year but less than every 6 months

Heart Failure Stage: _____

Marital Status: ☐ Married ☐ Divorced/Separated ☐ Single

Other medical or psychiatric diagnoses (illnesses for which you regularly see a doctor or take medication): _____
_____
_____
_____

Ethnicity:
☐ Asian or Pacific Islander ☐Asian Indian
☐ Black/African American (non-Hispanic) ☐ Caucasian/White
☐ Native American ☐ Latino/Hispanic ☐ Puerto Rican
☐ More than one race (specify): _____

Appendix D: Planned Methods Not Used in Emergent Design

Planned Method	Change Made	Rationale
Sampling only through the cardiology units at the hospital	Sampling through the cardiology units as well as via private social media heart failure support groups	Restricted hospital access was implemented for visitors and non-essential hospital staff when COVID-19 emerged in the area (late March 2020). This made the target population at the hospital inaccessible to the PI.
Using only the cardiology unit charge nurses or supervisors to identify potential participants	Integrating the Heart Failure Nurse Navigator as the primary person to identify and initially approach potential participants	There were staffing changes related to COVID that made it necessary for the charge nurses and nursing supervisors to take on a patient assignment. This meant that they were unable to perform the role outlined in the planned method. The heart failure nurse navigator was also an embedded staff member with access to the target population but was not pulled in to take a patient assignment, leaving this individual open to assisting with recruitment.
Second interviews to expand and clarify topics from the first narrative interviews.	Second interviews were not conducted.	First interviews rendered sufficient detail and depth, making second interviews unnecessary. During first interviews, narrators universally began to repeat themes at the end. This signaled a kind of narrative saturation. I interpreted this to mean that participants were unlikely to share additional information or detail during second interviews.
All interviews were to be conducted outside of the hospital setting, in the participant's home or community.	Some participants were interviewed in their hospital rooms.	Participants interviewed in their hospital rooms were slated for discharge to nursing homes or restorative care environments. During COVID-19, nursing homes and restorative care facilities restricted access to visitors, making these participants inaccessible post-discharge. Interviews were conducted before discharge. The interview time was coordinated with the participant’s nurse at a time that avoided scheduled care activities. A sign was also placed on the door to indicate that an interview was in progress. This strategy was successful, and no substantive interruptions occurred.

Appendix E: Interview Guide

Initiation:

I'm studying how spirituality affects a person's experience with heart failure. Spirituality may include religion but also can be as simple as what gives your life meaning, purpose, a sense of connection, or a sense that you can get outside of yourself or immediate circumstances. I'm interested in these kinds of things and how any of them may play into your life experience before heart failure and during heart failure.

I would like to ask for permission to record this interview. Recording is important to support research analysis later because it preserves your story using your words. I plan to store this recording in a secure place so that the research team members are the only ones who have access to it. I will also use a fake name for you when I write the research report.

There are some risks and benefits of participation that I would like to discuss with you. First, your story has the potential to help health care researchers and providers understand better the experiences of patients who have heart failure. This could improve care for others in the future. Some people also find it helpful to just share their experience – it is sort of therapeutic for them. Sometimes I ask questions that will prompt you to talk about difficult events or feelings. This may also be a long interview. So, if at any time you feel like you don't want to continue, please let me know and we will stop. I have access to mental health resources that can help you if you need to talk to someone about these difficulties.

Would you like to proceed?

I want to give you a bit of information about how narrative interviewing usually works. Instead of using a question-and-answer format, narrative interviews give you an opportunity to tell your story. I will try not to interrupt along the way as you talk about your experience.

After you've had a chance to tell your story, I might ask some additional questions to clarify some things you've said.

If you're ready, let's get started…

"Some people have defined spirituality as a combination of finding meaning and purpose in life and feeling connected to something. What does spirituality mean to you?"

Then follow with "Tell me the story of your spiritual life since you first learned you had heart failure to the present."

[Add prompts regarding meaning, purpose, connectedness, and transcendence as necessary for clarification.]

Second interview guide (these did not occur):

Last time we talked I asked you to tell me your story. I've listened to that story and read the transcript. I'd like to talk to you more about that.

1. *[Share a list of participant's narrated experiences from the first interview grouped into chronological chapters.] Imagine these were to be put in a book about your spiritual life with heart failure. What title would you give each chapter?*
2. *[Go through chapters with the participant.] Would you add or change anything in each chapter?*
3. *Last time we talked about X, could you tell me more about that?*
4. *When we talked last you discussed X, could you explain how that affected Y?*
5. *When you mentioned X last time, I felt like there was another story there, would you mind tell me that story?*
6. *Some people say that things change after they become sicker, others say it does not make much difference. What about you?*
7. *How has spirituality impacted you during your illness?*
8. *Who is the hero of that chapter and why?*
9. *If you were to rewrite this story, how would you change it?*

Appendix F: UMKC IRB Approval

UMKC Institutional Review Board
University of Missouri-Kansas City

5319 Rockhill Road
Kansas City, MO 64110
816-235-5927
umkcirb@umkc.edu

December 03, 2019

Principal Investigator: Amanda Marie Emerson
Department: Nursing - General

Your IRB Application to project entitled "A Narrative Analysis of Spiritual Coping in Individuals with Terminal Heart Failure" was reviewed and determined to qualify for IRB exemption according to the terms and conditions described below:

IRB Project Number	2018082
IRB Review Number	255542
Funding Source	Sigma Theta Tau ¿ Alpha Iota Chapter
Initial Application Approval Date	December 03, 2019
IRB Expiration Date	N/A
Level of Review	Exempt
Project Status	Active - Exempt
Exempt Categories	45 CFR 46.101b(2)
Risk Level	Minimal Risk
HIPAA Category	HIPAA Authorization

Approved Documents
exempt-research-information-sheet.docx
Updated HIPAA authorization form obtained MU - the study and recruitment site.
Letters of support from the advisor and the instituition from which particpants will be recruited.
Demographics data collection form
Interview guides
Dissertation Proposal

The principal investigator (PI) is responsible for all aspects and conduct of this study. The PI must comply with the following conditions of the determination:

1. No subjects may be involved in any study procedure prior to the determination date.
2. Changes that may affect the exempt determination must be submitted for confirmation prior to implementation utilizing the Exempt Amendment Form.
3. The Annual Exempt Form must be submitted 30 days prior to the determination anniversary date to keep the study active or to close it.
4. Maintain all research records for a period of seven years from the project completion date.

If you are offering subject payments and would like more information about research participant payments, please click here to view the UM system Policy on Research Subject Payments: https://www.umsystem.edu/oei/sharedservices/apss/nonpo_vouchers/research_subject_payments

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VITA

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