The purpose of this study was twofold: (1) to explore advance care planning (ACP) engagement activities, and (2) to examine ACP engagement determinants among Muslim community-dwelling adults living in the United States. Through the Social-ecological Model, ACP contributing factors were conceptualized into intrapersonal, interpersonal, and community factors. This study used a cross-sectional correlational design. A self-administered questionnaire was administered either in-person or online to measure ACP engagement, intrapersonal, interpersonal, and community factors. Convenience and snowball sampling methods were used to recruit Muslim adults from Islamic organizations in a Southeastern state in the United States.

A racially diverse sample of 148 Muslim adults with ages ranging from 18 to 79 years participated in the study. The participants’ average scores of engagement in ACP activities were relatively low, and ranged from 1.97 (SD = 1.22) to 2.09 (SD = 1.34). About two-thirds of the participants were in the precontemplation stage. Several intrapersonal and interpersonal factors, but none of the community factors, were associated with ACP engagement. The final analysis showed that 6 intrapersonal factors and 1 interpersonal factor predicted the participants’ mean of ACP engagement. The predicted mean of ACP engagement increased for those who were born in the United States, who self-identified as Asian Americans, who had awareness and knowledge about ACP, who knew a deceased one who received aggressive end of life (EOL) medical
treatments, and who acculturated with American culture. The predicted mean of ACP engagement decreased for those who knew a deceased one who received minimal EOL medical treatments. No significant ACP engagement differences were found according to gender and age.

New knowledge was developed about ACP among Muslims living in the United States. Understanding the contextual factors that determine Muslim adults’ engagement in ACP behavior is vital to identify culturally appropriate healthcare programs that would assist this minor growing segment of the population in patient-centered health care, as well as to expand efforts to improve wellbeing. Study findings inform implications in the areas of practice, education, health policy, and future research to alleviate disparities in ACP.
ADVANCE CARE PLANNING ENGAGEMENT AMONG MUSLIM COMMUNITY-DWELLING ADULTS LIVING IN THE UNITED STATES OF AMERICA

by

Ghaith Ahmad Bani Melhem

A Dissertation Submitted to the Faculty of The Graduate School at The University of North Carolina at Greensboro in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy

Greensboro 2019

Approved by

Debra C. Wallace
Committee Chair
In the Name of Allah (God), the Entirely Merciful, the Especially Merciful

This work is dedicated to my family for their patience, endless love, and understanding as I have completed this journey.
This dissertation, written by Ghaith Ahmad Bani Melhem, has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

Committee Chair
Debra C. Wallace

Committee Members
Judith A. Adams
Karen Amirehsani
Sudha Shreeniwas

October 22, 2019
Date of Acceptance by Committee

October 22, 2019
Date of Final Oral Examination
ACKNOWLEDGMENTS

First of all, I express gratefulness to Alhamdulillah (الْحَمْدُ ﷺ), which means all the praises and thanks be to Allah (God), who generously helped me throughout this journey. This dissertation would not have been possible without his will and permission.

I would like to express my sincere gratitude to the faculty and staff at the University of North Carolina at Greensboro for providing me with the opportunity, resources, and support for completing this academic work. Special thanks to my dissertation chair, Dr. Debra Wallace, for your patience, guidance, encouragement, and endless support for this work over the past 3 years. To my committee professors, Dr. Judith Adams, Dr. Karen Amirehsani, and Dr. Sudha Shreeniwas, I am incredibly grateful for your assistance, knowledge, and suggestions throughout my project. To the faculty at UNCG, with special recognition to Dr. Robin Bartlett, Dr. Susan Letvak, Dr. Thomas McCoy, and Dr. Ratchneewan Ross for your ongoing support and for motivating me and encouraging me on my journey. To my friends, cohort, and coworkers, for your support and for not letting me give up. I am very grateful to the Muslim community and leaders, who supported my research with your time and wisdom.

I would thank my family in Jordan (my parents, sisters, brothers, and my parents-in-law), thank you so much for all of your prayers, love, support, and encouragement during this journey of completing my Ph.D. It has been quite an adventure for all of us. This dissertation process would not have been possible, first without Allah’s permission, and then without your love, support, and encouragement.
I would never forget my wife, Ala, and our two kids—Rama, and Hashem; no amount of words can express the love I have for you and the excitement I feel for getting to share in each of your lives every day. Just know that you all are the—lights of my life and mean more to me than I can ever express. I am truly blessed to have you all in my life.
# TABLE OF CONTENTS

List of Tables ............................................................................................................. ix

List of Figures ............................................................................................................. x

## CHAPTER

### I. INTRODUCTION ................................................................................................1

- Purpose of the Study .......................................................................................... 5
- Background and Significance ............................................................................ 5
  - Advance Care Planning (ACP) ....................................................................... 7
  - Muslim Americans ...................................................................................... 10
- Significance ........................................................................................................ 13
- Theoretical Framework for Understanding Muslim Americans’
  Engagement in ACP (Social Ecological Model) ........................................... 14
  - Intrapersonal Factors ................................................................................. 16
  - Interpersonal Factors .................................................................................. 17
  - Organizational/Institutional Factors ............................................................ 18
  - Community Factors ..................................................................................... 18
- Public Policy ..................................................................................................... 19
- Definitions ......................................................................................................... 21
  - Intrapersonal Factors .................................................................................. 21
  - Interpersonal Factors .................................................................................. 21
  - Community Factors ..................................................................................... 21
- Research Questions .......................................................................................... 22
- Chapter Summary .............................................................................................. 22

### II. REVIEW OF THE LITERATURE ....................................................................24

- Introduction ..................................................................................................... 24
- Intrapersonal Factors ...................................................................................... 25
  - Demographic Characteristics ................................................................... 25
  - Socioeconomic Status ............................................................................... 36
  - Health Status and Past Experiences ............................................................ 38
  - Knowledge about Advance Care Planning ............................................... 40
  - Attitudes toward ACP ............................................................................... 45
  - Intrapersonal Factors among Muslims ....................................................... 50
- Interpersonal Factors ....................................................................................... 53
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Sample Description ($N=148$)</td>
<td>111</td>
</tr>
<tr>
<td>Table 2</td>
<td>Proportion of Participants at Each Stage of Change for All ACP Activities</td>
<td>115</td>
</tr>
<tr>
<td>Table 3</td>
<td>ACP Engagement Score Differences among Participants ($N=148$)</td>
<td>117</td>
</tr>
<tr>
<td>Table 4</td>
<td>Participants’ Preferred Decision-making Styles ($N=148$)</td>
<td>139</td>
</tr>
<tr>
<td>Table 5</td>
<td>Correlations between ACPE and Participants’ Intrapersonal, Interpersonal, and Community Factors ($N=148$)</td>
<td>140</td>
</tr>
<tr>
<td>Table 6</td>
<td>Simultaneous Multivariable Linear Regression Analysis of ACPE of Muslims Living in the United States ($N=148$)</td>
<td>141</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

Figure 1. The Social Ecological Model of the Advance Care Planning Engagement (SEM-ACPE) ................................................................. 20
CHAPTER I
INTRODUCTION

The healthcare system of the United States has experienced a transformational change in models of decision-making related to an individual’s health. The dominant paternalistic approach that gives the exclusive authority to the medical team to make decisions on behalf of patients has transformed into a shared decision-making model (Kilbride & Joffe, 2018). Through self-determination, the latter model involves a partnership between patients and their healthcare providers to make decisions that are congruent with their values and preferences (Igel & Lerner, 2016). Shared decision-making tools in the healthcare industry have been associated with positive outcomes (Elwyn et al., 2012). These positive outcomes include, but are not limited to, improving patients’ knowledge, achieving more realistic expectations, making decisions congruent with patients’ preferences and wishes, reducing decisional conflicts among parties, and improving productive patient involvement in planning for their healthcare (Austin, Mohottige, Sudore, Smith, & Hanson, 2015; Oczkowski, Chung, Hanvey, Mbuagbaw & You, 2016; Stacey et al., 2014).

Given the importance of shared decision-making in healthcare, Healthy People 2020 health promotion goals focus on promoting shared decision making in the healthcare system. One goal of Healthy People 2020 is “to increase the proportion of persons who report that their health care providers always involve them in decisions
about their health care as much as they wanted” (Healthy People 2020, 2007). Therefore, finding approaches that improve the American population’s participation in making decisions related to their health has become one of the current research priorities in the United States (American Academy of Nursing on Policy [AAN], 2012; National Institutes of Health, 2018).

Shared decision-making has been increasingly recognized as a national priority to facilitate engagement in making decisions related to health care (Healthy People 2020, 2007). However, a preliminary domestic survey by the National Institutes of Health (NIH) and the National Cancer Institute (NCI) in 2007 found that only 51.6% of Americans reported participating in making decisions related to their health (NIH & NCI, 2014). Although Healthy People 2020 has aimed to increase the percentage of Americans participating in making decisions related to their health from 51.6% to 56.8%, data have shown only a 0.6% of increase between 2007 and 2014 (NIH & NCI, 2014).

Shared decision-making is especially important when it comes to making difficult decisions, such as those that occur in serious illness or near the end of life (EOL), when many people are not capable of actively engaging in decision-making. Often, the result is that family members are faced with making emotionally difficult decisions without knowing loved one’s wishes. Given this challenge, in addition to the fact that the time of an individual’s death is difficult to be determined accurately, some organizations who advocate for terminally ill patients have initiated efforts for supporting advance care planning (ACP) (Institute of Medicine [IOM], 2015). In the 2015 report, *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life*,
the Institute of Medicine (IOM) emphasized ACP as a method to facilitate decision making at the EOL of seriously ill Americans (IOM, 2015). Similarly, palliative, hospice, and EOL care organizations have supported ACP for seriously ill people (IOM, 2015; National Coalition for Hospice and Palliative Care, 2018; Periyakoil, Neri & Kraemer, 2016). The American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association have considered the documentation of surrogate and patient’s preferences of care, both of which are ACP-related activities, as two quality indicators of hospice and palliative care (Dy et al., 2015).

The core value of ACP is identifying an individual’s treatment preferences before they become unable to communicate (Austin et al., 2015). People who engage in ACP can explore, discuss, and communicate their values, beliefs, preferences, and wishes with their health care providers and their family members so that if they become incapable of communicating, their wishes can be known and honored (IOM, 2015; Rietjens et al., 2017; Sudore, Lum, et al., 2017). Advanced care planning enables people to have conversations about their physical, psychological, social, and spiritual needs and concerns (Rietjens et al., 2017).

Although ACP conversations involve discussions about EOL issues, these discussions can occur at any stage of life. A recent Delphi panel of experts in palliative and EOL care defined ACP as

>a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness. (Sudore, Lum, et al., 2017, p. 821)
People are encouraged to initiate ACP conversations with their families and healthcare providers at any stage of their lives, not just at the EOL stage. Similarly, it is recommended that all adults should be engaged in ACP conversations, regardless of their age, gender, race, or health status (IOM, 2015; Sudore, Lum, et al., 2017). Given the dynamic nature of an individual’s personal preferences over time, it is recommended that ACP documents be revised and updated throughout life (Sudore, Lum, et al., 2017).

Although there is some conflicting evidence of the rate of ACP engagement, a recent meta-analysis of findings published from 2011 to 2016 estimated the engagement rate at 36.7% (Yadav et al., 2017). Disparities in the ACP engagement rate exist. A high rate of engagement was found among those who had a chronic disease, who were in advanced age, who had higher income and education, who were White, and who were palliative or hospice care recipients (Rao, Anderson, Lin, & Laux, 2014; Sudore et al., 2018; Yadav et al., 2017). A low rate of engagement has been reported among racial and ethnic minorities, lower educated people, people with lower socioeconomic status, younger people, rural residents, and non-English speakers (Barwise, Wilson, Kashyap, Gajic, Pickering, 2016; Harrison, Adrion, Ritchie, Sudore & Smith, 2016; McAfee, Jordan, Sheu, Dake & Kopp Miller, 2019; Rao et al., 2014; Smith, 2008; Sudore et al., 2018; Yadav et al., 2017). Indeed, the existing evidence on ACP disparities has revealed significant variation in the quality of EOL care and death across all the groups (IOM, 2015).

One minority group about which little is known in the area of engagement in ACP are Muslim Americans. Although there are 3.45 million Muslims living in the United
States (Pew Research Center, 2018a), minimal literature exists describing the engagement in ACP by Muslims. Understanding of the engagement in ACP among Muslims living in the United States should assist this growing segment of the population in patient-centered health care, as well as expand efforts to improve well-being and to add new knowledge about this ethnically diverse population.

**Purpose of the Study**

The purpose of this study was twofold: (1) to understand ACP engagement in a sample of Muslim community-dwelling adults living in the United States, and (2) to explore determinants of their ACP engagement. The current study examined engagement in four ACP activities: (1) completion of an ACP formal document, (2) designation of a health care proxy, (3) discussion with a substitute decision-maker types of medical treatment preferences, and (4) discussion with healthcare providers regarding medical treatment preferences. Moreover, this study explored whether relationships existed between ACP engagement and other potential influential factors (constructs) conceptualized based on the Social Ecological Model (SEM) of McLeroy, Bibeau, Steckler and Glanz (1988).

**Background and Significance**

Health care decisions at or near the EOL are difficult for individuals, families and health care providers (Dillworth et al., 2016). Decisions such as whether to initiate or terminate life support can be emotionally charged and can leave family members with feelings of regret and guilt, especially if they are not aware of what the person would have wanted (Dillworth et al., 2016; Laryionava et al., 2018). These decisions are also
emotionally difficult for health care professionals who might not understand the patient’s values or know the patient’s preferences for EOL treatment (Dillworth et al., 2016; Periyakoil, Neri, & Kraemer, 2015).

End of life treatment decisions were historically informal in the United States until the passage of the Patient Self-Determination Act in 1991. The passage of this federal law required hospitals and other healthcare facilities funded by Medicare to: (1) provide written documents that exhibit patients’ right to make decisions about their healthcare as well as written policies that ensure respect of this right by healthcare providers and institutions, (2) maintain records about an individuals’ advance directive (AD) status, (3) respect individuals’ choices and never force them to receive medical treatments, (4) comply with the state laws that control AD, and (5) educate professionals and the public about issues regarding patient self-determination and AD (Senate Bill 5067, 1990; Paris & O’Connell, 1991). However, passage of this act and ensuing attempts to encourage people to complete ADs was disappointing (IOM, 2015). Recently the focus of ACP has been to move decision making upstream by encouraging health care providers to have ACP discussions early in the disease trajectory and on an ongoing basis, rather than waiting until a person is hospitalized, facing a life-threatening illness, diagnosed with a terminal condition, or facing nursing home placement. Health care decisions, especially EOL decisions, are personal and require ACP (IOM, 2015). Instead of focusing just on completion of legal documents (living will and health care power of attorney), the focus is on having ongoing discussions with health care providers and family members. In addition, appointing a health care proxy who knows and agrees to
abide by a person’s preferences is encouraged (National Hospice and Palliative Care Organization, 2017; Sudore, Heyland, Lum, et al., 2017).

**Advance Care Planning (ACP)**

An ACP conversation encompasses much more than just a recommendation to complete legal documents. Advanced care planning might include: giving individuals and their families information about the available treatment options, identifying individuals’ acceptance or rejection of any medical treatment options, communicating personal preferences and wishes with their families, choosing one or more individuals to make decisions on behalf of the patient, and completing a written document that includes an individual’s treatment choices to use when he or she becomes unable to communicate with others (National Hospice and Palliative Care Organization, 2017). There is no one typical action corresponding to ACP (Fried, Bullock, Iannone & O’Leary, 2009; Fried et al., 2010; Rietjens et al., 2017). Although ACP related activities vary in the literature, the following are common: (1) execution of a living will, (2) designation of a health care proxy, (3) discussion of patient’s preferences regarding life-sustaining medical treatment with family and/ or health care professionals a, (4) discussion of a patient’s preferences regarding quality versus quantity of life with family and/ or health care professional (Fried et al., 2010; Fried et al., 2018; Sudore, Heyland, Lum, et al., 2017).

Engagement in any ACP activity has been recognized as a health behavior in which people can be identified by their stage of change (Fried et al., 2010). Stages of change of ACP engagement are: precontemplation, contemplation, preparation, action, and maintenance (Fried et al., 2010; Simons-Morton, McLeroy & Wendel, 2012). Thus,
while a person who has no interest to engage in ACP would be in the precontemplation stage of change, a person who develops awareness of need to engage in ACP would be classified in the contemplation stage. When a person starts planning to engage in ACP within the upcoming time, they would be in in the preparation stage of change. Actual participation in one of the ACP activities within six months indicates that a person is in the “action” stage, but participation for six month or greater indicates that the person in the “maintenance” stage (Freid et al., 2010; Sudore, Heyland, Barnes, et al., 2017).

Currently, several documents can be used to record patients’ preferences. These documents are classified into legal documents and medical orders (National POLST Paradigm, 2017). The legal documents refer to the advance directive, which includes living will and health care power of attorney (Carr & Luth, 2017). The living will was the first ACP document developed in the United States (Cook, 2008; Towers, 1978).

According to Sabatino (2010), “the living will model sought to offer something inviting to both individuals and physicians. To individuals, it offered a standardized tool to express their wishes about life-sustaining treatment—usually to withhold or withdraw it—in the event of a terminal condition or permanent unconsciousness. To physicians, the living will offers statutory immunity if they complied with the patient’s wishes in good faith” (p. 213). Health care power of attorney, also called proxy or surrogate, refers to a preauthorized person who can make decisions on behalf of an individual when he/she becomes unable to communicate (Carr & Luth, 2017; IOM, 2015).

The second type of ACP document, medical orders, involves professional instructions that must be followed by healthcare professionals when an individual faces a
critical change in his/her health status. Usually, these orders are written and signed by the primary healthcare provider of a seriously ill individual whose life expectancy is less than a one-year (National POLST Paradigm, 2017). *Do-not-resuscitate, do-not-intubate,* and *do-not-hospitalize* are examples of medical orders that can be mutually agreed upon between providers, patients, and families during ACP discussions (IOM, 2015; National POLST Paradigm, 2017). In addition to these documents, other documents, such as the *Organ and Tissue Donation Form, Physician Orders for Life-Sustaining Treatment* (POLST), and *Medical Orders for Life-Sustaining Treatment* (MOLST) have emerged (National Institute on Aging, 2018).

Emerging evidence has revealed many positive outcomes of engagement in ACP conversations. Engagement in ACP discussions is associated with higher completion rates of advance directives and high quality of communication about preferences regarding medical treatments with family members and healthcare providers (National Hospice and Palliative Care Organization, 2017; Oczkowski et al., 2016). For people who were at the end of their lives, engagement in ACP has been associated with improvement in patient outcomes, such as reduction in unwanted life-sustaining therapies and aggressive medical treatments (such as feeding tubes, antibiotics, and surgery), increase in the use of comfort care (palliative and hospice care), decrease in-hospital admissions and deaths of individuals who are terminally ill, higher compliance with following patients’ preferences, and higher family and patient satisfaction, and high quality of both life and death (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014; Detering, Hancock, Reade & Silvester, 2010; Khandelwal, et al., 2015).
As a method that improves public participation in making decisions related to their health, ACP discussions can benefit patients, families, healthcare providers and systems (Jimenez et al., 2018; Lum, Sudore, & Bekelman, 2015). However, Americans vary in their perceptions, attitudes, knowledge, awareness, and preferences regarding ACP (Rao et al., 2014). For example, in populations of Asian Americans, Latinos, African Americans, and Russian American seniors, researchers have found a low level of knowledge and awareness about ACP (Dobbs, Park, Jang & Meng, 2015; Eckemoff, Sudha & Wang, 2018; Gao, Sun, Ko, Kwak & Shen, 2015; Ko & Berkman, 2012; Kwak & Salmon, 2007; Wittenberg-Lyles, Villagran & Hajek, 2008). Some cultural beliefs hindered participation in ACP. For example, for some African Americans, Asian Americans, and Russian Americans discussing topics related to death and dying was seen as culturally unacceptable and to be avoided (Eckemoff et al., 2018; Glass, Chen, Hwang, Ono & Nahapetyan, 2010; Johnson, Kuchibhatla & Tulsky, 2008; Yap, Chen, Detering & Fraser, 2018). In addition, many Asian American seniors prefer more indirect communication and were more comfortable when ACP discussions were initiated by their healthcare providers (Gao et al., 2015; Ko & Berkman, 2012; Yonashiro-Cho, Cote & Enguidanos, 2016).

**Muslim Americans**

One of the minor faith communities in the United States is the community of the followers of Islam, or Muslims (Clark, 2010). The estimated number of Muslim Americans in the United States varies based on national reports. However, according to the Pew Research Center, there are 3.45 million Muslims in the United States, forming
1.1% of the total population (Pew Research Center, 2018a). The majority of Muslim Americans (58%) are immigrants with a variety of racial and ethnic backgrounds, languages, and countries of origin: 20% are from South Asia, 14% from Middle East/North Africa; 13% from other Asia/Pacific, 5% from Sub-Saharan Africa, 2% from Europe, and 2% from Americas other than the United States (Council on American-Islamic Relations (CAIR), 2012; Pew Research Center, 2017; Pew Research Center, 2018b). While the majority (41%) of Muslims living in the United States self-identified as White, approximately one quarter (28%) are Asian, and one-fifth are Black, with roughly half of Muslim Blacks converted to Islam (Pew Research Center, 2018b; Pew Research Center, 2019). Although Muslim Americans are a diverse population, they share a common religion that informs life affairs, belief systems, and behaviors (Pew Research Center, 2018b).

Although the Muslim American community has a significantly younger median age than the national median age (Pew Research Center, 2015), by 2030 the number of Muslim American seniors age 60 years or older is projected to increase from 140,000 to 570,000 (Pew Research Center, 2015). This tripling of the older group implies a growing need for Muslim Americans to engage in ACP.

Although Muslim Americans are culturally and socioeconomically diverse, they share a religion that shapes most behaviors, including those related to health (Boucher, Siddiqui & Koenig, 2017; Padela & Curlin, 2013; Padela et al., 2018; Padela, Killawi, Heisler, Demonner & Fetters, 2011). Islam has a unique ethico-legal framework that guides Muslims’ tradition of decision making (Padela & Curlin, 2013). In brief, the
ethico-legal framework involves three domains that inform health-related behaviors: proscription, prescription, and permission. Proscription includes behaviors that are explicitly prohibited, such as drug and alcohol use. Prescription encourages some behaviors that might have positive outcomes, such as physical activity and breastfeeding. The third domain, permission, includes behaviors that are neither prohibited nor encouraged, such as marriage to a first cousin (Padela & Curlin, 2013). However, the way that Islamic traditions might influence ACP engagement behavior among this population is not well studied.

Evidence has shown that decision making among Muslim Americans is highly influenced by their religious leaders, who are called imams (Inhorn & Serour, 2011). Most Muslim families and patients ask for religious advice from their imams and consider this advice as equal to the medical advice (Padela et al., 2011). Based on the Islamic ethics and laws that most imams learn during professional education, imams are able to help other Muslims in making decisions related to their health (Padela et al., 2011). However, some Muslim imams in the United States have had insufficient training and education about healthcare and the healthcare system (Ali, Milstein & Marzuk, 2005; Padela et al., 2011).

Through the formal religious statements, called fatwas, imams issue opinions about an individual case or public cases (Inhorn & Serour, 2011). Islamic bioethical organizations can issue fatwas to declare religious opinions or recommendations about matters of public concern. For example, the Islamic Medical Association of North America (IMANA) recommends that all Muslims should have a living will, advance
directive, and a case manager for their care, to help physicians to know their wishes, when he or she is unable to give directions (IMANA Ethics Committee, 2005, p. 37). The extent to which imams and Islamic bioethical organizations affect the decisions made by patients and their families in ACP has not been well examined.

Several potential barriers to ACP exist for Muslim Americans. Currently, the majority of the available materials that teach people about ACP are written in English. Estimates are that 17% of Muslim Americans have limited English proficiency (Pew Research Center, 2009). Limited English proficiency might be an influential factor in engagement in ACP among Muslim Americans. Also, most of ACP educational materials are available online, which requires internet services and electronic devices that are not affordable for all people. Lack of awareness about ACP is common among American immigrants who are non-English speakers; this lack of awareness contributed to a low engagement in ACP among non-English speakers (Barwise et al., 2016; Gao et al., 2015; Yonashiro-Cho et al., 2016). However, the degree to which language barriers and access to technology can affect Muslim Americans’ behavior of engagement in ACP is understudied.

**Significance**

This study was essential because it addressed a lack of current research examining ACP engagement among Muslim Americans. Examining ACP engagement in this unique religious population could assist in identifying the potential effects of religious beliefs on ACP behaviors. Further, examining ACP engagement in Muslim American populations supports efforts to reduce the national disparities in ACP engagement that might not be
accounted for by race, ethnicity, and other sociodemographic characteristics. Understanding the ACP engagement behavior and its contributing factors informs the development of new interventional tools and programs targeted to the stage of behavior change of ACP engagement. Also, the understanding of Muslim American behavior of engagement in ACP provides a foundation for practical ways to promote participation in ACP and to ensure that the receipt of high quality of EOL care is consistent with values and preferences.

**Theoretical Framework for Understanding Muslim Americans’ Engagement in ACP (Social Ecological Model)**

Engagement in Advance Care Planning (ACP) is a multifactorial phenomenon (IOM, 2015). No one factor can separately explain engagement in ACP among adults. Given this evidence, the current study utilized the Social Ecological Model (SEM) of McLeroy and colleagues (1988) as a conceptual framework to understand Muslim Americans’ engagement in ACP and its related factors. One of the main strengths of SEM is its flexibility to be used not only to design and evaluate interventions, but also to analyze behaviors (McLeroy et al., 1988). Thus, through the lens of the SEM, Muslim Americans’ engagement in ACP was explored based on the multiple-level contextual perspective.

Historically, Urie Bronfenbrenner was the first scientist who applied ecological perspective from biology to describe psychological development among human beings (Bronfenbrenner, 1974; Bronfenbrenner, 1977). In the 1970s, Bronfenbrenner introduced a preliminary ecological conceptual framework and later, in the late 1980s, the ecological systems theory to explain the child’s development and potential contributing factors.
Bronfenbrenner’s ecological systems theory proposes that both an individual and the surrounding environment are affecting each other through reciprocal dynamic interactions over time (Bronfenbrenner, 1989). Based on Bronfenbrenner’s ecological perspective, the contextual influences on behavior are divided into multilevel system consisting of micro-, meso-, exo-, and macro-levels of influence (Bronfenbrenner, 1977).

Bronfenbrenner’s ecological explanatory perspective of person-environment interaction has become a cornerstone that other scientists have relied on to develop other conceptual frameworks that explain individuals’ behaviors with a consideration of the cumulative effect of multiple contextual factors (Simons-Morton et al., 2012). McLeroy et al.’s (1988) Social Ecological Model (SEM) for health promotion is one of those frameworks that has adopted Bronfenbrenner’s ecological perspective in order to explain health behaviors (McLeroy et al., 1988). The SEM has various applications in health behavior research, including behavior analysis, intervention development, and evaluation (Davis, Campbell, Hildon, Hobbs & Michie, 2015; Golden, McLeroy, Green, Earp & Lieberman, 2015; Sallis & Owen, 2015). For example, the SEM has been widely applied to develop programs that promote tobacco cessation and physical activity addressing the multiple levels of influence (Marcus & Forsyth, 2018; Sallis & Owen, 2015).

The SEM stresses the importance of considering the bidirectional nature of causation between an individual and the surrounding environment when explaining behavior or designing the interventional programs to promote a behavior (McLeroy et al. 1988). Additionally, the importance of considering the cumulative multiple level of
influence of surrounding environmental factors on an individual’s behavior, including physical, social and cultural ones is emphasized (McLeroy et al. 1988). Therefore, McLeroy et al. (1988) have suggested that human behavior can be explained by a five-level system of influence encompassing intrapersonal, interpersonal, organizational, community, and public policy factors (McLeroy et al., 1988). The following paragraphs review the five levels of influence, including how they can be defined and how they might influence behavior.

**Intrapersonal Factors**

Personal engagement in behavior can be influenced by several internal, invisible personal factors (McLeroy et al., 1988). In addition to personal demographic characteristics, such as gender, race, country of origin, language, and age, an individual’s intrapersonal level of influence might include other aspects such as knowledge, attitudes, behavior, religiosity, beliefs, motivation, self-concept, developmental history, past experience, and personal skills (McLeroy et al., 1988, p. 355). Some of these factors can have a significant effect on ACP engagement. For example, an individual’s knowledge about the importance, types, and effectiveness of ACP has been found to be an influential factor of ACP engagement, and people who had high level of knowledge about ACP were more likely to report participation in ACP than those who had lower level of knowledge (Campbell, Edwards, Ward & Weatherby, 2007; Mezey et al., 2000). Another example of the intrapersonal factor is the personal attitudes toward behavior (McLeroy et al., 1988). Individuals who had positive attitudes toward ACP were more prone to engage
in ACP than those who had negative attitudes (Campbell et al., 2007; Douglas & Brown 2002).

**Interpersonal Factors**

The second level of influence of SEM is the interpersonal level (McLeroy et al., 1988). People live and interact within social groups, which McLeroy et al. (1988) have called primary groups. Primary groups encompass “formal and informal social network and social support systems, including the family, workgroup, and friendship networks” (McLeroy et al., 1988, p. 355). The connection with people from any of these groups influences an individual’s decision making in terms of maintaining, engaging, or quitting a behavior (McLeroy et al., 1988; Rimer & Glanz, 2005). People are influenced by the opinions, thoughts, behavior, advice, and support of the people in their surrounding social groups (Rimer & Glanz, 2005). Therefore, in order to change individuals’ behaviors, the modifying the norms of social groups to which they belong must also change (McLeroy et al., 1988). With respect to ACP, the family plays a central role in all ACP-related behaviors (National Hospice and Palliative Care Organization, 2017). For example, in some communities, decision-making of medical treatments becomes a family responsibility when an individual becomes incapable of making their own decision (Gao et al., 2015; Ko & Berkman, 2012). In some cultures, people prefer that their families or a health care professional initiate the conversations about ACP (Gao et al., 2015). In the Muslim communities worldwide, the entire family, including the first-degree relatives and grandparents, may participate actively in the decision-making process (Beaty, 2015;
Organizational/Institutional Factors

At the organizational level, factors that influence and are influenced by an individual’s behavior can be defined as “rules, regulations, policies, and informal structures, which may constrain or promote recommended behaviors” (Rimer & Glance, 2005, p. 11). In addition to formal institution factors, like a workplace, informal factors, such as voluntary membership in faith, professional, or neighborhood organizations, are important in forming an individual’s social identity (McLeroy et al., 1988, p. 355). For example, members who belong to the same faith community have reported similar EOL preferences and wishes (Pew Research Center, 2013). A low rate of cervical cancer screening among female Muslim Americans due to lack of female providers is an example of an organizational factor that has affected individuals’ health care behaviors (Matin & LeBaron, 2004; Salman, 2012).

Community Factors

Community factors are “relationships among organizations, institutions, and informal networks within defined boundaries” (McLeroy et al., 1988, p. 355). Community as a construct has three independent meanings: (1) mediating structures or face-to-face primary groups to which individuals belong,” (2) “the relationships among organizations and groups within a defined area, such as local voluntary agencies, local governmental health providers, local schools, etc.,” and (3) “a population which is coterminous with a political entity, and is characterized by one or more power structures”
All of the community-related factors, under all the three mentioned definitions, are essential, influential factors that shape individual social identity and connect individuals to the broader social environment (McLeroy et al., 1988). Using nine national churches as intervention sites for the Center for Practical Bioethics’ (CPB) project to promote ACP behaviors among African Americans is one example of the importance of considering community role in shaping behaviors (CPB, 2015).

**Public Policy**

Public policy is a set of local, state, and national laws and policies that regulate individuals’ behaviors and maintain social environment (McLeroy et al., 1988). The regulatory mechanism of public policy can be by: (1) prohibiting behaviors, such as banning smoking in public locations; (2) providing incentives to directly or indirectly encourage behaviors; and (3) establishing supportive public resources, such as state public health departments (McLeroy et al., 1988). The new Centers for Medicare and Medicaid Services’ (CMC) policy to reimburse healthcare providers for the time spent during ACP conversations is a good example of how public policy could affect ACP engagement among the American population (CMC, 2015).

The SEM expands the scope of influence from a small singular level to a broader one that includes multiple levels (Harper, Steiner & Brookmeyer, 2018). This expansion has allowed assessment, intervention, and evaluation studies or programs to include influential environmental factors in addition to the personal ones (Sallis & Owen, 2015). On the other hand, lack of specificity about the most proposed behavior-contributing
factor is one of the SEM limitations (Sallis & Owen, 2015; Harper et al., 2018). Also, it is not clear how constructs of each level in SEM interact with each other in each situation and behavior (Sallis & Owen, 2015).

The SEM guided this study to examine ACP engagement in Muslim community-dwelling adults living in the United States. As can be seen in Figure 1, three SEM constructs were examined: intrapersonal factors, interpersonal factors, and community factors. The SEM guided development of operational definitions and selection of measures for each of the three constructs. Data were collected from Muslims living in the United States to answer the research questions. Implication of findings was implemented in the context of organizational and public policy factors.

Figure 1. The Social Ecological Model of the Advance Care Planning Engagement (SEM-ACPE). © Bani Melhem, 2019. The constructs of “intrapersonal factors,” “interpersonal factors,” and “community factors” were adapted from McLeroy, Bibeau, Steckler, and Glanz (1988).
**Definitions**

The following definitions of the three main constructs adopted from the SEM were used in this study.

**Intrapersonal Factors**

The term “intrapersonal factors” means the distinctive personal qualities that might affect behavior, which in this study is engagement in ACP. In addition to sociodemographic characteristics and the history, an individual’s intrapersonal factors might include knowledge, attitudes, behavior, and religiosity.

**Interpersonal Factors**

Interpersonal factors refer to social relationships and ties that a person builds with other surrounding people or social groups that can impact one’s engagement in ACP. The essential component of the interpersonal level of influence is “primary group,” which encompasses “formal and informal social network and social support systems, including the family, workgroup, and friendship networks” (McLeroy et al., 1988, p. 355).

**Community Factors**

This study conceptualizes the concept “community” as a “face-to-face primary groups to which individuals belong” (McLeroy et al., 1988, p. 363). Thus, “community factors” was be used in this study to refer to the Muslim community-related factors that play key roles in Muslim Americans’ behavior of engagement in ACP.
Research Questions

This study answered the following research questions:

1. What are the ACP engagement behaviors used by Muslim community-dwelling adults living in the United States?

2. What intrapersonal factors were associated with the ACP engagement among Muslim community-dwelling adults living in the United States?

3. What interpersonal factors were associated with the ACP engagement among Muslim community-dwelling adults living in the United States?

4. What community factors were related to the ACP engagement among Muslim community-dwelling adults living in the United States?

5. What combination of intrapersonal, interpersonal and community factors were associated with ACP engagement among Muslim community-dwelling adults living in the United States?

6. What were the differences between age and gender groups regarding ACP engagement among Muslim community-dwelling adults living in the United States?

Chapter Summary

Patient decisions on health treatment require multiple levels of consideration. Increasingly, health technology, surgical techniques, and new pharmacological treatments can extend life physically. However, increased longevity, terminal illness, and other chronic health conditions require quality of life and patient centered treatment decisions. Advance care planning is a major strategy to encompass these considerations and make
personal decisions known. Inherently, ACP benefits individuals and the entire community in terms of facilitating decision-making when an individual becomes incapable of making decisions on their own. The estimated rate of Americans’ engagement in ACP is inconsistent but mostly lower than the national target/objective. However, disparities within the American population regarding ACP engagement are common among minority groups. To improve the national ACP engagement rate, understanding ACP engagement behavior among minorities is crucial. Muslim Americans are a minority faith community whose ACP engagement is understudied.

The Social Ecological Model guided this study to assist in the understanding of ACP engagement among Muslim Americans. Through the lens of SEM, this study proposed that ACP engagement among Muslim Americans is a multifactorial behavior that can be explained by multiple levels of influence. This study sought to understand ACP engagement behavior and contributing intrapersonal, interpersonal and community factors among Muslim community-dwelling adults living in the United States. Six research questions were identified. Findings of this study provided a foundation on which to provide patient centered and culturally competent care. In addition, the study allowed the perspective of the Muslim American community regarding ACP to be known.
CHAPTER II
REVIEW OF THE LITERATURE

Introduction

Participation in advance care planning (ACP) is a vital behavior for all people to improve the quality of EOL care (IOM, 2015). Although the prevalence of engagement in ACP varies widely in the literature, the average proportion is mostly lower than the national objectives. The lowest ACP engagement rate is among minority populations. However, causes of disparities in ACP engagement have been the subject of intense debate within the scientific community. Uncovering contextual factors that contribute to participation in health-related behaviors has been identified as a crucial element for providing health promotion programs (Simons-Morton et al., 2012). Therefore, understanding the contextual factors that determine people’s engagement in ACP behavior is vital to identify culturally appropriate patient-centered healthcare programs that would promote participation in such behavior (Choi, McDonough, Kim & Kim, 2018; Ko & Lee, 2014).

This chapter presents a review of ACP relevant literature. Through the lens of the Social Ecological Model (SEM), this chapter discusses the most common cited contextual and environmental influential factors under three primary levels of influence: intrapersonal, interpersonal, and community factors. Because of the scarcity of research that addressed ACP engagement among Muslims living in the United States, this chapter
discusses findings from research that involved minority populations and Muslims living in countries other than the United States.

**Intrapersonal Factors**

Intrapersonal factors or intrapersonal level of influence refer to personal characteristics that might affect American adults’ engagement in ACP. In addition to personal sociodemographic characteristics such as gender, race, and age, intrapersonal factors might include other aspects, such as knowledge, attitudes, behavior, religiosity, beliefs, motivation, self-concept, developmental history, past experiences, and personal skills (McLeroy et al., 1988, p. 355). Based on this review, many factors conceptualized under the intrapersonal level of influence were found to be associated with ACP behavior. The following paragraphs focus on the most common intrapersonal characteristics discussed in the literature, specifically, demographic characteristics, socioeconomic status, health status and experience, and knowledge about and attitudes towards ACP.

**Demographic Characteristics**

Central to the intrapersonal factors is the set of demographic characteristics. The term demographic was derived from two Greek words: *demos*, which means people; and *graphy*, which means picture (Salkind, 2010). The demographic characteristics are independent variables that provide descriptive information about the representative sample of a population (Salkind, 2010). It is highly recommended that a researcher should select only a set of self-reported demographic variables that help to understand the underlying phenomenon of interest (Salkind, 2010). Therefore, the following paragraphs
review the most common demographic variables that were found to be potentially associated with ACP engagement.

**Age**

Age is a demographic factor that has been widely cited as correlating with engagement in ACP. Several national reports and studies have noted that the prevalence of engagement in ACP increases with older age (Choi et al., 2018; McAfee et al., 2019). For example, a national survey of 7,946 American adults indicated that 51.2% of adults older than 65 years had executed an advance directive (AD) compared with only 11.8% of those ages younger than 34 years of age (Rao et al., 2014). Similar findings were reported by another recent national study, which reported a significantly high ACP engagement among older adults, aged > 65 years, compared to younger ones (39% and 21%, respectively) (McAfee et al., 2019). Similarly, the prevalence of ACP among older adults belonging to minority groups was higher than in younger adults. One study that included a relatively large number (2,609) of Asian Americans, found a significantly higher completion rate of ADs reported by people older than 39 years with the highest proportion (22%) among those ages older than 60 years and the lowest (5.8%) for those under 39 years of age (Jang, Park, Chiriboga, Radhakrishnan & Kim, 2017).

Most studies in the field of ACP behavior have only focused on older adults. There has been little exploration of ACP engagement among healthy young adults. As of 2019, only three published studies examining ACP engagement among healthy young adults were found in the literature (Schnur & Radhakrishnan, 2019). All three studies were cross-sectional descriptive, recruited college students from American universities,
and reported information about ACP engagement, perspectives, and prevalence (Kavalieratos, Ernecoff, Keim-Malpass & Degenholtz, 2015; Tripken & Elrod, 2018). However, only two studies provided information regarding ADs completion rate (Kavalieratos et al., 2015; Schnur & Radhakrishnan, 2019). In one study that comprised a sample of 56 young American adults, aged between 18-30 years, only 2% reported having an AD (Kavalieratos et al., 2015). A similar rate (2%) was reported in a recent cross-sectional study involving 147 young Americans, aged 18-26 years (Schnur & Radhakrishnan, 2019). The two studies provided information about young American adults’ engagement in ACP behaviors other than completion of ADs, such as communication of medical treatment preferences with others. The prevalence of assigning a healthcare proxy was low and the same as the prevalence of ADs. Only 2% of young adults who participated in the Kavalieratos et al. (2015) study, and 5% of those in Schnur and Radhakrishnan (2019) study confirmed having a designated healthcare proxy.

The previous study results demonstrated that the prevalence of conducting informal ACP conversations among young American adults was more common than the completion of ADs and holding formal ACP discussions. In Kavalieratos et al.’s (2015) study, the researchers found that the percentage of young American adults who undertook ACP conversations with parents was 27%, with a partner was 9%, with a friend was 4%, and with other relatives was 2%. On the other hand, only 2% of young adults reported having formal ACP conversations with a healthcare provider (Kavalieratos et al., 2015). Similar findings in a study of ACP in young adults revealed that 35% of young adults had informal ACP discussions with family and friends compared to less than 1% who had
formal ACP discussions with a healthcare provider (Schnur & Radhakrishnan, 2019). Unlike the two aforementioned studies, the third study that examined ACP among young adults reported only engaging in informal ACP conversations. Consistent with the other two mentioned studies, 36% of a sample of 310 young American adults had informal ACP conversations (Tripken & Elrod, 2018).

The likelihood of participation in ACP increases with older age. Researchers in a study of 1,523 adults living in Canada and British Columbia found that older age was positively associated with conducting ACP discussions with either family, friends, or healthcare providers (Teixeira et al., 2015). Moreover, older age was positively associated with higher completion of ACP documents and with a higher rate of the designation of a healthcare proxy (Teixeira et al., 2015). In another study of 1,823 older British adults, researchers found that per one additional year in age, there was a 50% increase in the likelihood of completion of ACP documentation (Musa, Seymour, Narayanasamy, Wada & Conroy, 2015).

Several studies have examined age difference in ACP engagement in minority populations. The results of those studies in minority American demonstrated a similar positive relationship between age and ACP engagement. In a study that included a diverse racial sample (Whites, Blacks, Latinos, and Asians) the researcher examined the relationship between age and ACP engagement by analyzing data obtained from a relatively large national sample of 2,111 adults aged 18-64 years (Carr, 2012). The findings demonstrated that older age was significantly associated with more engagement in ACP (Carr, 2012). Specifically, with each one-year increase in age, the likelihood of
having a living will increased by 6%, and the possibility of having ACP conversations increased by 3% (Carr, 2012). Similar findings were reported by Moorman and Inoue (2013) in their examination of the relationship between age and completion of either ADs or having informal ACP discussions in a population of 21,150 racially diverse American adults aged 18–64. Age was positively associated with higher completion of an AD, with one year of age increasing the likelihood of completing an AD by 4% (Moorman & Inoue, 2013). Also, age was associated with a higher occurrence of informal ACP discussions, with an increase of 3% of informal ACP discussions for every one additional year of age (Moorman & Inoue, 2013).

The association between age and ACP engagement was also examined in single ethnic minority populations. Dobbs and colleagues (2015) examined predictors of ADs completion among a sample of 675 community-dwelling Korean American older adults. The findings showed that after controlling for other tested variables, older age was the only significant predictor for the likelihood of having an AD (Dobbs et al., 2015). In another study that included a relatively large number (2,609) of Asian Americans, between the ages of 18 and 98, researchers found a significant difference in ADs completion rate between age groups (Jang et al., 2017). Similar to previous studies findings, the older adults (60 years and older) were 4.6 times more likely to complete ADs than their counterparts from other age groups (Jang et al., 2017).

**Sex/Gender**

Sex is another demographic variable that was examined within the ACP literature. One study of 7,946 American adults demonstrated that women were significantly more
likely to have ADs than men (Rao et al., 2014). Similar findings were observed by Choi et al. (2018). In particular, self-identified female sex was positively associated with higher ACP documentation, having a living will or the designation of a healthcare proxy (Choi et al., 2018). In another study of 1,523 adults who were from Canada and British Columbia, women were found to be more likely than men to engage in informal discussions regarding ACP (Teixeira et al., 2015). A study in Britain had similar findings; British older men were 50% less likely than women counterparts to complete an ACP document (Musa et al., 2015). This held true in minority groups as well. In a study of Korean Americans, women were 1.6 times more likely than men to be aware of advance directives (Dobbs et al., 2015). Being a female was significantly associated with having an AD completed (67% vs. 41% in the non-completion group) (Alano et al., 2010). In a cross-sectional study involving 310 young American adults, men were less likely than women to report awareness about ADs and healthcare proxy designation (Tripken & Elrod, 2018).

Other studies found no gender differences in ACP engagement. For example, among a sample of 2,111 adult Americans, Carr (2012) found no significant differences between men and women regarding having a living will, ADs, a healthcare proxy, and conducting ACP conversations (Carr, 2012). In a cross-sectional study involving 147 students aged 18–26 years, there were no significant gender differences regarding the level of knowledge of, attitudes toward, or preparedness to engage in ACP (Schnur & Radhakrishnan, 2019). In Zhang et al.’s (2015) study there were no gender differences between Chinese older adults (65 years old) regarding their awareness and attitudes
towards ACP. Also, no gender difference was found among a sample of young African American adults (aged 21-40) regarding their knowledge, attitudes, and use of ADs (Ramsey, 2013).

**Marital Status**

Marital status has been examined for its association with ACP engagement. However, unlike the other demographics, it was minimally examined. Overall, there was no consensus in the literature about the presence of a significant association between ACP engagement and marital status. Some studies indicated a relationship between ACP engagement and being married, while the findings of other studies failed to support this relationship. In a retrospective analysis study of 7,946 American adults, those persons who had gotten married were significantly more likely to execute an AD than unmarried persons (Rao et al., 2014). However, the findings of another national retrospective study that involved 8,926 American adults, demonstrated that being married was related to a 31% lower likelihood of completing a living will and 22% lower likelihood of signing a healthcare proxy (Choi et al., 2018). In a Cross-sectional survey study of 1,195 American adults, no significant difference between being married and unmarried regarding the completion of ADs was found (Pollack, Morhaim & Williams, 2010).

Marital status was also examined for its relationship with other variables that might influence ACP engagement, such as knowledge of, attitudes toward, or readiness to engage in ACP. However, contradicting results were reported. For example, in a cross-sectional study including 386 adult Americans, aged 40-80 years, there were no statistically significant differences noted by marital status in intentions to complete living
wills or healthcare proxy designation or to engage in informal ACP conversations (McAfee et al., 2019). Further, there were no significant associations between marital status and level of knowledge of, attitudes toward, or preparedness to engage in ACP (Schnur & Radhakrishnan, 2019). Conversely, Dobbs et al. (2015), who recruited 675 community-dwelling Korean American adults, found that married adults were two times more likely to have awareness about ADs than unmarried counterparts.

**Race and Ethnicity**

Investigating the association between race and ethnicity and engagement in ACP is a continuing concern within the literature. Generally, the prevalence of ACP engagement among minority populations is lower than that of the majority population. Being an African American older adult (≥ 65 years) woman was associated with a lower likelihood of having ACP documents and participating in ACP conversations (27% vs. 41%) (Kang, Bynum, Zhang, Grodstein & Stevenson, 2019). In studies of the relationship of race and ethnicity in completing ADs in the marginalized people, African Americans in addition to Hispanics were found to be were less likely to report having ADs than their White counterparts (Ko & Berkman, 2012; Ko & Lee, 2014; Rao et al., 2014). The findings of one of these studies showed that, compared to one-third of Whites who reported completion of ADs, less than one-fifth of African Americans and Hispanics reported completing ADs (Ko & Lee, 2014). A cross sectional study that included 386 adult Americans, aged 40-80 years found a relatively low engagement in ACP (25% of allay participants); however, there were significantly higher engagement rates among
Whites compared to Hispanics and blacks (33%, 18%, and 8% respectively) (McAfee et al., 2019).

The disparity in ACP engagement exists in several ACP related activities. A recent randomized cross-sectional study that included 386 adult Americans aged 40-80 years demonstrated disparity in ACP engagement in three ACP activities among racial groups, including completion of a living will, designation of a healthcare proxy, and informal ACP conversations (McAfee et al., 2019). In that study, Whites had significantly higher engagement in all three activities than their black and Hispanic counterparts. The overall ACP engagement for the three racial groups White, Hispanic, and Black Americans was 33%, 18%, and 8% respectively (McAfee et al., 2019).

Similarly, in a retrospective national study that involved 9,228 American adults, self-identification as a Caucasian was associated with higher probability of engagement in ACP (Orlovic, Smith & Mossialos, 2019). Using retrospective observational design analyzing the Health and Retirement Study dataset, which is a national representative dataset including a sample of 9,228 adults of 50 years of age and older, these researchers found that African Americans were 69%, and Hispanics were 68% less likely to have executed a living will compared to their Caucasian counterparts (Orlovic et al., 2019). Moreover, they were 50% and 51%, respectively less likely than their white counterparts to engage in ACP discussions (Orlovic et al., 2019). The likelihood of engagement in a legal meeting regarding ACP was about three times lower among African Americans and Hispanics than their white counterparts (Orlovic et al., 2019). Minority populations were more likely than the majority one to engage in ACP at a time nearing death (Orlovic et
al., 2019). In particular, African Americans and Hispanics engaged in ACP at a time nearer to death than their White counterparts, with an average of 19 months closer to death (Orlovic et al., 2019). Overall, the probability of having a living will or a healthcare proxy was about 50% lower for racial minority populations than Caucasians (Orlovic et al., 2019). In another retrospective analysis of data included 8,926 American adults, there was about 61% of Whites assigned a healthcare proxy compared to 40% African Americans and 29% of Hispanics (Choi et al., 2018). Further, 61% of Whites completed a living will, but only 31% of African Americans and 22% of Hispanics completed one (Choi et al., 2018).

The low rate of engagement in ACP among minority populations has been challenged by Carr (2012). The researcher analyzed national data from the National Center for Family and Marriage Research, which included information about 1,075 American couples (aged 18-64 years) from four racial groups, Whites, Blacks, Latinos, and Asians and included information about participants' responses regarding engagement in ACP (Carr, 2012). Participation in ACP was measured by asking whether a person had a designated healthcare proxy, a living will, an AD, or informal declaration of preferences with somebody (Carr, 2012). Overall, 24% of participants executed either living wills or ADs, 27 % designated healthcare proxies, and the most substantial proportion (57%) reported having ACP conversations with others (Carr, 2012). The preliminary analysis revealed that Hispanics were significantly less likely than Whites to have living wills and less likely than Blacks to designate a healthcare proxy; however, Asians were more likely than Blacks and Whites to report having living wills (Carr,
2012). Compared to other racial groups, the White group reported the highest rate of having ACP conversations (60%); however, after the researcher adjusted for the other variables, including sociodemographic ones, the only significant difference that remained was between Asians and Whites. In particular, Asians were 56% more likely than Whites to have living wills (Carr, 2012).

Few studies have explored whether or not race is a predictor of disparities in ACP engagement. In a cross-sectional descriptive study, McAfee et al. (2019) examined what combination of race and other sociodemographic variables were associated with ACP engagement among the diverse racial group. The findings failed to support that race alone can explain disparities in ACP engagement (McAfee et al., 2019). After the researcher adjusted for sociodemographic variables, perceived norms, and attitudes toward ADs, the race became non-influential (McAfee et al., 2019). A retrospective study found that disparities in executing an AD and a living will disappeared between racial groups when people have any non-curable illnesses. The researchers concluded that having any chronic disease might encourage racial minority groups to engage in ACP (Choi et al., 2018).

Similar findings were reported by Ko and Lee (2014). These researchers conducted a cross-sectional study to examine the influence of race/ethnicity on ADs completion among 256 low income older adults (≥ 60 years old). The results showed that older adults from minority racial groups were less likely to have ADs. However, the effect of race on the completion rate of ADs disappeared after controlling for the other examined variables (knowledge, attitudes, healthcare system mistrust, social support, and socioeconomic status). Therefore, the researchers concluded that disparities in ACP among racial groups
could be explained by the integrative effect of other contextual and cultural variables rather than the race only (Ko & Lee, 2014).

Although some studies found that race was a factor in the engagement in ACP, those that controlled for other variables found that race alone is not a factor in the level of engagement in ACP. People from different racial and ethnic groups have different cultural, religious, and spiritual values and beliefs that might influence engagement in ACP (Choi et al., 2018). Furthermore, social relationships and family ties are different among racial groups and might affect ACP engagement. Cultural, religious and social factors were discussed later in this chapter.

**Socioeconomic Status**

Socioeconomic status is an intrapersonal factor that plays a fundamental role in the level of engagement in ACP. Throughout this chapter, the term “socioeconomic status” was used based on the Centers for Disease Control and Prevention (CDC) definition, “a composite measure that typically incorporates economic, social, and work status” (CDC, 2014a).

Higher education and income are associated with higher engagement in ACP (Carr, 2012; Choi et al., 2018; McAfee et al., 2019; Woosley, Danes & Stum, 2017; Orlovic et al., 2019). In a cross-sectional study including 386 adult Americans, aged 40-80 years, there were significant differences in engagement in ACPs by education and income (McAfee et al., 2019). People who self-reported having at least $70,000 of annual revenue had a higher engagement in ACP (34%) than those whose yearly income was less than $70,000 (22%) (McAfee et al., 2019). This study also found that those with a
bachelor’s degree had significantly higher in engagement in ACP than those with a community college degree 28% and 20% respectively (McAfee et al., 2019).

Similarly, within a sample of 2,111 adults aged 18-64 years Carr (2012) found that those with a college education had an 88% higher likelihood of completion of living wills than those without a college education. However, the study found no significant relationship between the level of education and having informal ACP discussions (Carr, 2012). Three recently published retrospective national studies that involved a combined number of 19,353 American adults found that the level of education and household income was positively associated with engagement in ACP activities, including executing an AD or a living will, engaging in ACP meetings, or signing a healthcare proxy (Choi et al., 2018; Orlovic et al., 2019; Woosley et al., 2017).

Studies have examined relationships between socioeconomic status and knowledge of, attitudes toward, or preparedness to engage in ACP (Gao et al., 2015; McAfee et al., 2019; Schnur & Radhakrishnan, 2019; Tripken & Elrod, 2018). Within a sample of 385 community-dwelling older Chinese American, those who reported higher education levels and higher incomes were more likely to have awareness about ADs (Gao et al., 2015). Similarly, compared to undergraduate students, graduate students were less likely to show awareness about ADs (Tripken & Elrod, 2018). Also, compared to employed young adults, unemployed young adults were less likely to know about the healthcare proxy, AD, and living wills (Tripken & Elrod, 2018). On the other hand, there were no significant associations between personal income and level of knowledge of, attitudes toward, or preparedness to engage in ACP (Schnur & Radhakrishnan, 2019). In
a cross-sectional study that included 386 adults Americans, no significant differences were reported in intention to participate in ACP by education and income (McAfee et al., 2019).

**Health Status and Past Experiences**

Self-reported health status plays a critical role in engagement in ACP. Poor health status is associated with higher engagement in ACP (Carr, 2012; Choi et al., 2018; Musa et al., 2015). One retrospective national study of 8,926 American adults supported that the number of non-curable illnesses related positively with executing an AD and signing a healthcare proxy (Choi et al., 2018). The likelihood of completing an AD or signing a healthcare proxy increased by 9% with a new diagnosis of a non-curable illness (Choi et al., 2018). Similarly, in a study of 1,823 British older adults (≥ 65 years old), researchers found that British older adults who reported better health status were 40% less likely than their counterparts to complete ACP documents (Musa et al., 2015). Similar findings were observed by Carr (2012). In this study, having poor health was significantly associated with a higher completion rate of living wills and having informal ACP discussions (56% and 35%, respectively) (Carr, 2012). In a retrospective cross-sectional study including 21,150 racially diverse American adults (18–64 years old), Moorman and Inoue (2013) observed that poor self-reported health status was associated with a higher prevalence of informal ACP discussions (Moorman & Inoue, 2013), however, health status was not related to the completion of ADs.

In addition to the self-reported health status, having a past self-experience of EOL treatments is associated with better awareness of, and readiness to engage in ACP
(Amjad, Towle & Fried, 2014; Gao et al., 2015). Amjad and colleagues (2014) conducted a cross-sectional descriptive study that included 304 older adult Americans (≥ 60 years old) to explore the correlation between self-reported experience and one’s readiness to engage in ACP. The researchers found that living with a life-limiting disease or having a past personal experience of intensive medical treatment were positively associated with increased willingness to engage in ACP discussions (Amjad et al., 2014).

Another factor that is positively associated with engaging in ACP is being a witness to others’ EOL experiences (Amjad et al., 2014; Tripken & Elrod, 2018; Woosley et al., 2017). In a retrospective study of 1,199 American older adults, investigators found that people whose parents had engaged in ACP activities were more likely to engage in ACP themselves (Woosley et al., 2017). In the same vein, in a cross-sectional quantitative study of 304 American older adults observed that people who witnessed the EOL experience of others or who reported having an experience of a perceived artificially prolonged death of others had an increased readiness to engage in ACP activities themselves (Amjad et al., 2014). Other researchers found that experiencing a death or an advanced illness of a loved one was correlated with better knowledge and awareness of ACP (Tripken & Elrod, 2018). Two qualitative studies that were conducted in two Europe countries (Italy and Belgium) found that older adults who reported having good experience of the death of loved ones were more likely to have negative attitudes toward ACP (Ingravallo, 2018; Piers et al., 2013).

In a cross-sectional study involved 386 adults Americans, being diagnosed or having a family loved one who was diagnosed with a life-limiting disease with a life-
threatening illness increased the likelihood of engagement in ACP (McAfee et al., 2019). Findings of a qualitative study of community-dwelling adults living in Honolulu, Hawaii were consistent with these findings (Ward Research, Inc. 2017). One participant said,

I think having a terminal illness makes you think about it. With my two parents, me and my sisters were forced into it. Both of them went into an operation and when they came out they were dying. They had a stroke during the operation. They were brain dead, but they were on machines. They had wills, but no type of directive, so my sisters and I were arguing whether or not they should stay on the machines or pull the plug. That made me think that I didn’t want my kids to go through that at all. It was terrible. (Ward Research, Inc., 2017, p. 6)

Knowledge about Advance Care Planning

Under the intrapersonal level of influence, knowledge about ACP is one the determinants that have received considerable critical attention in ACP literature. Knowledge about the ACP has been used interchangeably with the awareness of ACP in the current research. However, awareness of ACP was frequently assessed by asking a simple, quick question like “have you ever heard about ACP.” Whereas, knowledge about ACP was evaluated by more complex measurements developed by authors such as Lee, Hinderer, and Friedmann (2015), Murphy, Sweeney, and Chiriboga (2000), and Tripken, and Elrod, (2018). However, inconsistent findings have been reported by studies that examined lay people’s knowledge and awareness regarding ACP.

Considering knowledge and awareness regarding ACP is a vital factor that should be considered when studying ACP engagement. Lack of awareness about ADs, which was mostly indicated by a statement like “I don’t know what advance directives are,” was the most stated reason for not executing an AD in a national study including 7,946
American adults (Rao et al., 2014). However, the review of the published literature found a lack of research investigating knowledge about ACP among healthy adults. In this vein, Kermel-Schiffman and Werner’s (2017) systematic review observed that between 1994 and 2016 there were only 15 studies that discussed aspects of ACP knowledge in nonprofessional adults, with only seven studies examining ACP knowledge among healthy community-dwelling adults. However, among the seven studies, there were only two studies that included young adults (aged 18 and above), two studies included people aged 21–40 years, and the other three studies included people aged 55 years and above. Further, the majority of studies examined ACP knowledge among lay people using the quantitative method, took place in the United States, and included older adults (Kermel-Schiffman & Werner, 2017).

Lack of awareness of, and knowledge about ACP were prevalent among racial and ethnic minorities such as Latinos, African Americans, Korean Americans, and Russian Americans (Dobbs et al., 2015; Eckemoff et al. 2018; Kwak & Salmon, 2007; Wittenberg-Lyles et al., 2008). For example, in a qualitative study, that included 20 older Korean American adults and 16 family caregivers, only four older adults (≥ 60 years old) were able to describe ADs. However, after the researchers explained what AD means, some of the participants showed a willingness to sign one, but others remained reluctant (Kwak & Salmon, 2007). Another example of such studies was conducted by Gao and colleagues (2015). The researchers recruited a sample of 385 community-dwelling older Chinese Americans. To identify participants’ awareness of ACP, the researchers asked participants an open-ended question of whether they had heard about ADs. Any
participant who was aware of ADs was evaluated for the level of knowledge about ADs. Knowledge about ADs was measured by seven true-or-false statements adopted from Murphy et al. (2000). While 20% of participants heard about ADs, only 10% of them had completed one (Gao et al., 2015).

As the largest racial minority population in the United States, African Americans were also examined for their awareness and knowledge regarding ACP. For example, Ramsey (2013) conducted a study using the mixed method research design to explore African Americans knowledge about three forms of ACP: advance directive, living will, or durable power of attorney. The study included 112 adult participants aged between 21-40 years. Data were obtained by using the Advance Directives Knowledge, Attitudes, and Utilization Questionnaire (ADKAUQ) and focus group interviews. Most participants reported a lack of awareness of ACP. While some of them were aware of living wills, no one was aware of ADs. Interestingly, African Americans who participated in the focus group interview reported confusion among the different documents being used to indicate ACP (Ramsey, 2013).

Gender and sexual minority population were investigated for their knowledge about ACP. For example, a cross-sectional study was carried out by Hughes and Cartwright (2014). In that study, 305 gender and sexual minority adults, who were 18 years or older and living in Australia, were explored for the level of knowledge about four legal documents used to plan for the EOL care options. The four legal documents were powers of attorney, guardian, the person responsible, and advance directives. Although the participants reported some awareness about the first three documents, they
were remarkably unaware of ADs. In particular, only 38% of them heard about ADs. However, the relationship between ACP knowledge and engagement was not examined in the study (Hughes & Cartwright, 2014).

Young American adults were investigated for their knowledge about ACP. By using the focus group methodology, Kavalieratos and colleagues (2015) explored knowledge about ADs among 56 adults aged 18-30 years. Although about half of the participants acknowledged that an AD includes medical treatment preferences that would be activated at the time when an individual shows incapability, one-fifth of them thought AD was the same as the last will (Kavalieratos et al., 2015). Also, lack of knowledge about ACP was found in a quantitative cross-sectional study involved 310 young American adults aged 18-30 years (Tripken & Elrod, 2018). Three-fifths of participants reported poor knowledge and awareness of ACP and AD. On the other hand, four-fifths were aware of living wills. One third said that the appropriate time to initiate ACP conversations is when a serious illness diagnosis would be confirmed. Further, two-thirds were unaware of the proper age to start ACP conversations, with 11% of them reporting that such discussions must be initiated at the age of 55 years or older (Tripken & Elrod, 2018).

Lack of the public’s awareness about ACP was common in developed countries other than the United States. In Canada, Teixeira et al. (2015) surveyed ACP awareness among a sample of 1,523 adults, aged between 45-54 years and living in Canada or British Columbia. The researchers assessed ACP awareness by asking the participants “whether they had ever heard of the term ACP.” The results indicated that only 16% of
respondents reported that they were aware of ACP (Teixeira et al. 2015). Exploring the public awareness of ACP was done in China as well. Zhang et al. (2015) asked 900 Chinese older adults to answer whether they have heard about ACP. Like Teixeira et al.’s (2015) a vast number of participants (78%) have no previous knowledge about ACP. Unlike Ko and Lee’s (2014) study, the two mentioned international studies did not examine the relationship between ACP awareness and engagement in ACP behaviors (Teixeira et al. 2015; Zhang et al. 2015).

In addition to lack of awareness and knowledge of ACP, misconception, and confusion between ACP documents and other legal ones was reported in the published research, mainly between AD, and the last will and the testament. This confusion was most common among racial and ethnic minority groups. For example, Lee, Hinderer, and Friedmann (2015) found there were only 11% of 71 Chinese American adult participants could differentiate between AD and last will. Similar findings revealed by West and Hollis (2012), who found that the majority of older African Americans thought AD was analog to the last will, and the testament. Similarly, this misconception was common among other minority groups such as Korean Americans and Russian Americans (Eckemoff et al., 2018; Kwak & Salmon, 2007). Another study revealed that African Americans were more likely than other racial groups to have a misconception of that execution “living wills” means waiving medical treatments while Hispanics were more likely than other groups to believe that living wills have to be completed by lawyers and there is no way to change it later (Jonnalagadda et al., 2012). The confusion view was found among young American also. Among 56 young Americans Kavalieratos et al.’s
study (2015), there was one-fifth of participants thought that ADs as the same as last wills (Kavalieratos et al., 2015).

Also, the relationship between knowledge and engagement in ACP was also tested in the literature. Ko and Lee (2014) studied the association between knowledge about ADs and the completion rate among a sample of 256 older adults in the United States. The researchers measured ACP knowledge by asking participants whether they had heard about AD and they asked the participants to define AD using their own language. Mentioning the critical elements of AD, such as document treatment wishes and designating a healthcare proxy, was considered knowing AD. The results showed that White participants reported higher knowledge than individuals from racial minorities. However, after controlling for the effect of other variables, the impact of race on ADs completion became nonsignificant. Knowledge about ADs was one of the most influential factors on ADs completion. Specifically, participants who reported a prior understanding of ADs were 15 times more likely to complete ADs than those who did not (Ko & Lee, 2014).

Attitudes toward ACP

Attitudes toward ACP is a critical intrapersonal factor that plays an essential role in ACP engagement behavior. As a concept, “attitudes” has three main characteristics: “(a) a mental state—conscious or unconscious; (b) a value, belief, or feeling; and (c) a predisposition to behavior or action” (Altmann, 2008. p. 146). According to Dawson (1992), “in social psychology, it (the concept of attitudes) refers to a disposition towards or against specified phenomenon, person or thing” (p. 473). Also, in the theory of
planned behavior, Ajzen (1991) conceptualized “attitudes toward the behavior” as one of the main determinants of one’s intention to engage in a particular behavior (Ajzen, 1991). In this line, Ajzen defined “the attitude toward the behavior” as “the degree to which a person has a favorable or unfavorable evaluation or appraisal of the behavior in question” (Ajzen, 1991, p. 188). Based on these definitions, “attitudes” might be toward a person, object, or situation and might be positive or negative cognitive (evaluative), affective (emotional), or behavioral response (Ajzen, 1991, Altmann, 2008. p. 146; Dawson, 1992). This implies

(a) a deliberate consideration of the value of an event or phenomenon, (b) a liking for, or a dislike of, a phenomenon, based on one's feelings towards it, and (c) a tendency to behave towards a given phenomenon, person or thing in a specified way (or to express the intention so to do). (Dawson, 1992. p. 473)

Attitudes towards ACP is one of the critical factors that predict individuals’ engagement in ACP behavior (Lovell & Yates, 2014). Evidence shows that holding positive attitudes toward ADs is one of the most significant factors that predict completion of ADs. In one cross-sectional study that included 256 racial minority older adults, Ko and Lee (2014) found participants’ attitudes towards ADs was one of the most influential factors on ADs completion. Specifically, per one-point increase in attitudes score, there was an additional 20% increase in the likelihood of completion of ADs (Ko & Lee, 2014). Likewise, McAfee et al. (2019) noticed that attitudes toward ACP, as well as perceived norms, were the only significant determinants of people’s intention to engage in ACP behavior.
Minority racial groups reported various attitudes toward ACP. One cross-sectional study which included 386 adults found that Whites held significantly higher favorable attitudes toward ACP behaviors compared to Hispanics and Blacks (McAfee et al., 2019). One cross-sectional descriptive study included 209 community-dwelling Korean older adults (aged 65 years or older) found positive attitudes toward ADs (Lee, Jung & Choi, 2016). Compared to Whites, African Americans were more likely to believe that ACP improves the quality of EOL (Bullock, 2011). Additionally, there were statements cited in a qualitative study that involved adults living in Honolulu indicated negative attitudes (Ward Research, Inc. 2017). For example, a female participant said: “My husband told me to write down what I want and give it to my son, who is probably going to do whatever he wants anyway.”

Individuals’ attitudes toward ACP were studied in Western cultures other than the United States. The first example of these studies is a qualitative study conducted by Piers et al. (2013) to explore Belgian older adults’ attitudes toward ACP. The researchers interviewed 37 seriously-ill older adults, aged 71-104, who was receiving healthcare in hospitals, nursing homes, or living homes in Belgium. Having a painful experience or concerns resulting from personal loss of loved ones, absence of a healthcare proxy or lack of trust with relatives, and maintaining self-determination with fewer family burdens were motivations to have positive attitudes towards ACP. On the other hand, those who had negative attitudes toward ACP reported having a good experience of the death of a loved one, and trusting families and healthcare providers to make the best decisions on behalf of them when they become incapables (Piers et al., 2013).
Another qualitative study that took place in another European country, Italy, found mixed, positive and negative attitudes toward ACP among older people (Ingravallo, 2018). The study involved 30 older adults and ten family caregivers. All the study participants were unaware of the term ACP. However, after clarifying the term, most of the participants expressed willingness to engage in such behavior. Those who had engaged in ACP thought that ACP helps to relieve family burdens when a loved one becomes incompetent. On the other hand, there were some participants felt that there was no need to engage in ACP because they either were trusting family members to make decisions on behalf of them or they favored to “live for the day” (Ingravallo, 2018).

Consistent negative attitudes were noted among two-thirds of 1823 British older adults (Musa et al., 2015; Samsi & Manthorpe, 2011). For example, in Samsi and Manthorpe (2011), older adults participants used some phrases indicating their negative attitudes toward ACP discussions such as “live for today,” “enjoy life to the maximum,” “not thinking much about the future,” and “not letting worries and problems affect life” (Samsi & Manthorpe, 2011, p. 54).

It seems that attitudes toward ACP vary among age groups. Interestingly, older adults are more likely than young ones to have positive attitudes toward ACP (Mignani, Ingravallo, Mariani & Chattat, 2017). In this line, a review of literature conducted by Sharp and colleagues (2013) found that the majority of studies that examined older adults found positive attitudes towards engagement in ACP discussions, with 61% - 91% of participants appreciated such discussions (Sharp, Moran, Kuhn & Barclay, 2013). Consistently, most Americans adults who aged 40-80 years who participated in McAfee
et al.’s (2019) randomized cross-sectional study, held favorable positive attitudes toward ACP. Specifically, a high proportion of participants viewed a living will as an advantageous, convenient, and easy to administer tool (81%, 71%, and 65% respectively). Additionally, more than 55% of participants perceived that the other two ACP behaviors, healthcare proxy designation and informal ACP conversations, were as like as living wills in terms of their beneficence, convenience, and simplicity (McAfee et al., 2019).

There was a scarcity of studies that explored young people’s attitudes toward ACP conversations. However, the few studies that were done reported contradicting findings; some of them found the young population is mostly having negative attitudes toward ACP, while others found positive attitudes. For example, in a qualitative study used semi-structured group interviews, Kavalieratos and colleagues (2015) explored to explore the participants’ attitudes toward ACP, among a sample of 56 young American adults aged 18-30 years. The researchers used four open-ended questions: “How comfortable do you feel making serious decisions about your own health care?,” “What would make you more comfortable?,” “Why do you believe that advance healthcare planning exists?,” and “When, if ever, do you believe that it is important to make your healthcare wishes known?.” In general, most participants viewed ACP as a primary method that helps adult people to self-determination and to communicate the treatment preferences. However, some participants believed that ACP is unnecessary, and they trusted other relatives to decide on behalf of them when they become terminally ill. Conversely to older adults’ positive attitudes towards ACP, some young participants
thought initiating ACP conversations is inappropriate for healthy young people, especially they had to imagine that they will be seriously ill and incapables. A quote from one participant was

I definitely could not [plan] now. I just can’t plan for my own death now . . . I’m too young. I’m just too healthy now. I guess what it would take for me to do it would be a brush with my own death and not even one of a family member . . . I guess I would just really have to feel that my death were close. (p. 4)

On the other hand, positive attitudes toward ACP were reported by young adults in other studies. For example, in a cross-sectional study involved 147 students aged 18-26 years. Participants’ attitudes toward ACP were measured by a tool developed by Fried et al. (2010). The instrument consists of 20 items assessing attitudes towards ACP pros, cons, and beliefs. Overall, the majority of participants expressed positive attitudes towards ACP, with 79% of them viewed that ACP is congruent with their values and beliefs. Additionally, positive attitudes were evident by a high percentage of participants (93%) who agreed with that quality is superior to the quantity of life, which is considered as one of ACP behaviors. Regarding the relationship between attitudes toward ACP and other measured characteristics, the findings indicated only one significant relationship existed with knowledge about ACP (Schnur & Radhakrishnan, 2019).

**Intrapersonal Factors among Muslims**

The research in ACP to date has tended to focus on racial minority groups rather than faith communities. Thus, few primary published researches have studied ACP topic among Muslims living in the United States. Accordingly, the influence of intrapersonal factors on Muslim Americans’ engagement in ACP has never been adequately studied.
The following few paragraphs review studies that have addressed ACP topics among Muslims living in the United States.

The first study that included Muslims living in the United States was a cross-sectional study conducted by Rahemi (2017). The purpose of the study was to explore the “end of life planning” among a sample of 135 Iranian Americans, with age 50 years and older. However, the majority of participants were Muslims (86%). Thus, the findings of the study were reviewed as it might reflect the perspective of Muslims living in the United States. The vast majority of the participants were self-identified as Iranian Americans, were born in Iran (97%), had some college or higher (78%), insured (84%), and had good health status. About one half (47.4) of the participants reported engagement in EOL planning, which was assessed by a question “Have you communicated your end-of-life healthcare wishes in writing and/or verbally?” (p. 97). Participants’ attitudes toward EOL planning were not described in the study. However, the researcher examined the relationships between attitudes toward EOL planning and other variables, including engagement in EOL planning, acculturation, healthcare system distrust, social support, and spirituality. Attitudes toward EOL planning was positively associated with engagement in EOL planning (written documents and conversations). Specifically, per one additional point in attitudes score, the likelihood of engagement in ACP increased by 12%. Also, the findings demonstrated positive associations between attitudes, and acculturation and healthcare system distrust ($r = 0.42$, and $r = 0.15$ respectively), but negative association with spirituality ($r = -0.22$).
The second study that addressed ACP among Muslims living in the United States is a recent study conducted by Rahemi, Dunphy, and Newman in 2019. Roughly, half of the participants (46%) reported engagement in ACP by either completing documents or having conversations. The researchers examined the associations between engagement in EOL planning and a set of intrapersonal factors, which were age, gender, spirituality, past losses, and healthcare insurance status. However, having experience of loss of a loved one was the only factor that was associated with engagement in EOL planning (Rahemi et al., 2019). Those who had experienced the death of a loved one were 3.45 times more likely to engage in EOL planning than those who had not had the same experience (Rahemi et al., 2019).

To summarize, the published articles that have examined influences ACP engagement behavior have revealed many influential factors that can be conceptualized under the intrapersonal level of influence. The most common intrapersonal factors cited in the literature were demographic characteristics, socioeconomic and health statuses, EOL experience, knowledge about ACP, and attitudes toward ACP. Overall, the literature has supported that the prevalence and the likelihood of engagement in ACP increases with: older age, female gender, having Caucasian race, greater income, higher education, poor health status, more significant number of chronic diseases, positive history of receiving medical treatment that provided for terminally-ill persons, experience of loss, having awareness about ACP, having knowledge about ACP, and holding positive attitudes toward ACP. Most of these studies have recruited older adult population, used cross-sectional design, and lacked for using theoretical/conceptual frameworks and
reliable, valid tools to measure the influential factors. Few studies have examined the effect of the intrapersonal factors on ACP engagement among Muslims living in the United States.

The findings regarding the associations between ACP engagement and intrapersonal factors vary in the published studies. Being an older adult or a female predicted a higher likelihood of having ADs than being a young or male adult. Unlike age and gender, marital status has shown inconsistent association with ACP engagement. The number of non-curable illnesses, history of receiving the EOL treatments, or experiencing a loss of a loved one were positively associated with engagement in ACP activities. Lack of awareness of and knowledge about ACP was dominant among racial and ethnic minorities and could lead to greater disparity in ACP engagement. Holding positive attitudes toward ADs was one of the most significant factors that predict completion of ADs.

**Interpersonal Factors**

The interpersonal level of influence encompasses the social ties that a person builds with other people or groups and may impact engagement in ACP behavior. The essential domain of interpersonal level of influence is “primary group.” The “primary group” encompasses “formal and informal social network and social support systems, including the family, workgroup, and friendship networks” (McLeroy et al., 1988, p. 355). People usually affect and are affected by their peers from the same social group by communicating opinions, thoughts, behavior, advice, and support (Rimer & Glanz, 2005). However, investigating the role of the interpersonal factors in ACP is a continuing
concern within the literature. The following paragraphs discuss the social network and acculturation as two interpersonal factors that play a role in engagement in ACP.

**Social Network and Support**

Based on the SEM, the social network seems to play an essential role in ACP behaviors. The family was one of the social groups critical to the decision-making process. Based on an ethnographic study conducted by Quinn et al. (2012), the family has eight informal roles central to the decision-making process. These roles were primary caregiver, primary decision maker, family spokesperson, out-of-towner, patient’s wishes expert, protector, vulnerable member, and health care expert (Quinn et al., 2012, p. 43).

Social network involvement in EOL decision making processes, including ACP, may improve the outcomes of patients and families. For example, social groups’ engagement in decision making regarding the EOL treatments was positively associated with high quality of EOL care (Parks et al., 2011; Sudore, Casarett, Smith, Richardson, & Ersek, 2014). In this context, Sudore, Casarett, et al. (2014) conducted a retrospective study by reviewing medical records of 34,290 deceased people from 146 veteran healthcare facilities. Family engagement in making decisions was assessed by investigating medical records within the last month of life of a dead person. The researchers found that deceased ones were more likely to receive a high quality of EOL care when their families involved in decision making. Compared to those whose families had no active engagement in the EOL decision-making, those who had family engagement were more likely to receive palliative care (odds ratio [OR] 4.32), spiritual
care (OR 1.48), died in hospice (OR 2.24), and signed a DNR order (OR 7.62) (Sudore, Casarett, et al., 2014).

In general, the social network may participate in ACP as assistance, or it may join as a decision-maker substitute (Bullock, 2011). One famous example of the social network as assistance is participation in informal ACP conversations, which are between a person and others from the social network. In this vein, compared to formal discussions (which is between a person and healthcare providers), engagement in informal ones was more dominant. Among 21,150 American adults aged 18-64 years, 55% self-reported engagement in informal ACP compared to only 28% of them had ADs (Moorman & Inoue, 2013). Similarly, In Teixeira et al.’s (2015) study, 52% of Canadian adults reported having informal ACP discussions, compared with only 10% of them having formal ACP discussions. Ingravallo (2018) found that all the study participants, 30 Italian older adults had just informal ACP discussions, with none of them held formal ACP discussions or documents. Designating a healthcare proxy, also called surrogate decision maker, is an example of the social network as a decision-maker substitute. A healthcare proxy is “a decision maker that makes medical decisions when the patient becomes incapacitated and the individual did not previously identify a medical durable power of attorney” (Lum et al., 2015, p. 392).

Although McAfee et al. (2019) found that more than two-thirds (72%) of the adult population would engage in ACP if they were encouraged by their families, research findings have indicated that people vary in the preferred ones who may communicate with them to convey their preferences and wishes. While 94% of young American
participants chose their parents as the best individuals to have with them ACP discussions, there were 44% of them preferred talking to grandparents, 35% to siblings, 27% to partner, and 26% to a friend (Tripken & Elrod, 2018). Further, most people choose a family member to be a healthcare proxy when they become incapables (Kavalieratos et al., 2015; Tripken & Elrod, 2018). However, people vary in their choices. For example, in Kavalieratos and colleagues’ (2015) study, young Americans chose either parents, partners, or partners and parents together to be their healthcare proxies (Schnur & Radhakrishnan, 2019).

Previous studies have reported a positive relationship between the social network and engagement in ACP (Kang et al., 2019; Schnur & Radhakrishnan, 2019; Woosley et al., 2017). For example, Kang and colleagues (2019) conducted a retrospective secondary data analysis included 6017 older community-dwelling American women aged 66 to 93 years. Social support was measured by the Berkman-Syme Social Network Index (Berkman, & Syme, 1979). The findings indicated that a woman who had low social support were 15% less likely than those who were socially supported to report having an ACP documentation or conversation. Further, compared to women who had emotional support, those who reported inadequate emotional support were 16% less likely to be engaged in ACP conversations and documentation. Living alone as long with having a loss of a loved one increased the likelihood of engagement in ACP by 20%, for both documentation and conversations (Kang et al., 2019). Similarly, in a cross-sectional study that involved 355 Japanese older adults, the researchers observed a positive relationship between social support and engagement in ACP conversation. Indeed, those who had
adequate social support were about three times more likely to engage in ACP conversations than those who had limited social support (Miyashita et al., 2019).

Based on the literature, social support seems to be associated with engagement in ACP. However, some scholars hypothesize that other variables mediate this relationship. To examine this hypothesis, Lee and colleagues (2013) conducted a cross-sectional descriptive study including 209 community-dwelling Korean American older adults. The researchers examined the relationship between attitudes toward ADs engagement and two other variables; social support, and decisional conflict. The preliminary analysis indicated a positive association between social support and attitudes toward ADs. However, the advanced analysis found a negative mediating effect of decisional conflict on this relationship (Lee et al., 2016).

As discussed before, social support has been seen as a critical supportive resource for people to engage in ACP. However, some studies observed no or negative association. A retrospective national study that involved 8,926 American adults living with loved ones showed no association with executing an AD or signing a healthcare proxy (Choi et al., 2018). Also, living with a spouse or with children associated negatively with having written end-of-life preferences (Orlovic et al., 2019). Additionally, sometimes the role of social members might be changed from a supportive one to coercive or persuasive one (Sedig, 2016). Therefore, some healthcare workers perceived that family involvement in decision making might be a challenge that might affect people engagement in ACP (Kwak, Ko, & Kramer, 2014). For example, nurses and other healthcare providers have reported that, although they were convinced with the futility of some medical treatments,
they felt obligated by surrogates or family members to provide these treatments (Aghabarary & Nayeri, 2016; Palda et al., 2005; Sibbald, Downar & Hawryluck, 2007).

**Acculturation**

The concept “acculturation” “comprehends those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original cultural patterns of either or both groups” (Redfield, Linton & Herskovits, 1936, p. 149). John Wesly Powell was the first one who used the term “acculturation” in an 1880 report by the U.S. Bureau of American Ethnography (New World Encyclopedia, 2018). Some scholar argued that acculturation in the United States reflects the degree of Americanization that immigrants acquire (Wright et al. 2013).

Two levels of acculturation were suggested: (1) group-level, in which cultural change occurs at the community level; and (2) psychological acculturation, in which the culture change happens at the personal level (Graves, 1967). Based on acculturation, people’s behavior in a new culture might be one of the followings: (1) maintaining the beliefs and values held from primary culture, (2) holding a bicultural views mixed from both the primary and secondary cultures, and (3) adopting a new belief system stemmed from the secondary or the new culture (Cruz-Oliver, Talamantes, & Sanchez-Reilly, 2014).

Acculturation is a central cultural factor for immigrants’ lives (Jang et al., 2017). Therefore, it is one of the cited factors that play a role in ACP engagement among minority immigrant populations (Hong, Yi, Johnson, & Adamek, 2018). Evidence
showed that with greater acculturating, the likelihood of engagement in ACP surges up. For example, per one extra point in the acculturation scores, there was 12% in the likelihood of executing an AD among Korean American adults (Dobbs et al., 2015). Consistently, Kelley and colleagues found that the possibility of completing ADs was associated positively with acculturation among Latinos. Specifically, per one additional point in the acculturation, there was a 60% increase in the likelihood of having an AD (Kelley, Wenger, & Sarkisian, 2010). On the other hand, the adverse impact of acculturation on having family discussions about ADs was reported among Latinos (Wittenberg-Lyles et al., 2008).

Jang et al. (2017) examined the effect of acculturation, education, and knowledge on the completion of ADs. The study included a multigenerational sample of 2,609 marginalized Asian Americans of ages of 18 years or older (Jang et al., 2017). Asian American adults who reported greater acculturation were significantly more likely to have ADs than those who had a lower level of acculturation (14.2% vs. 6.8%). A notably higher rate of completion (36.6%) was observed within the participants who reported better knowledge of ADs in comparing with participate who had weak knowledge (5.3%). Thus, the researchers examined whether the relationship between knowledge of completion rate was strengthened by interaction with acculturation or education. Findings indicated that knowledge was more likely to be linked to the ADs completion among those with a higher level of education (Jang et al., 2017).

It seems that acculturation associated with better awareness of ACP. This evidence was supported in ACP research that targeted minority racial populations. In this
line, the acculturated older Chinese Americans in Gao et al.’s (2015) cross-sectional study reported higher awareness of ACP. Accordingly, the likelihood of being aware of ADs increased among those who had higher acculturation and lived in the United States for 20 years and more. In particular, per one additional point in acculturation, there was a 40% increase in the likelihood of being knowledgeable about ADs. Furthermore, the possibility of knowing ADs was about seven times higher among those who lived for 20 years or more in the United States (Gao et al., 2015). Similarly, Dobbs et al. (2015) found that community-dwelling Korean American adults who reported higher levels of acculturation were more likely to be more aware and knowledgeable about ADs and to have written ADs. Precisely, per one extra point in the acculturation scores, there was a 9% increase in the likelihood of being knowledgeable about ADs (Dobbs et al., 2015).

Some scholars have suggested that the variation in attitudes towards ACP between immigrants and people from their primary culture might be explained by acculturation. For example, completing formal ADs was rejected among Japanese living in Japan but accepted by Japanese living in the United States (Bito et al., 2007). Also, acculturation has affected Japanese immigrants’ views about the aspects related to the end of life. With exposure to the American culture, the following behaviors became accepted within the Japanese community who are living in America: (1) to tell patient with medical diagnosis became socially accepted, (2) lower acceptance of that physicians make decisions without family and patients participation, (3) acceptance of executing formal ADs, and (4) lower obligations on family regarding caregiving for the critically sick patient (Bito et al., 2007).
The literature has highlighted considering acculturation as a key element that may explain the ACP knowledge gap among different generations of racial minority immigrants. For example, Eckemoff et al. (2018) noticed that first-generation immigrants have lower knowledge about ACP than their second-generation counterparts. The researchers conducted a qualitative study to explore Russian immigrants’ perspectives about the end of life. When comparing with second-generation immigrants, first-generation Russian immigrants had lower awareness about ACP including living wills and advance directives. Further, first-generation Russian immigrants confused living wills with the financial last wills and testaments, which include information about personal property. Although talking about ACP and death seems a taboo topic in Russian culture, the second-generation immigrant Russians felt more comfortable than those from the first generation to speak with others about ACP and death. Here an example of a second-generation Russian participant’s view about ACP:

I think that within families it’s essential to discuss these things realistically . . . we all die and that is an essential part of life and that is how I raised my children . . . as difficult as it is . . . it must be discussed . . . when people get older things do happen, like . . . a person can fall down and then they have some injury . . . then they need help, so . . . they need to know what sort of things they want and discuss that with their family. (Eckemoff et al., 2018, p. 237)

**Interpersonal Factors among Muslims**

As previously discussed, interpersonal factors encompass social relationships and groups that a person interact within his life. Social relationships are vital for Muslims worldwide (Beaty, 2015). The role of social groups with Muslim communities become highly prominent when someone or a group encounters a devastating situation such as
illness or death (Duffy, Jackson, Schim, Ronis & Fowler, 2006). Yet, the primary research that has examined the effect of interpersonal factors on Muslim Americans’ engagement in ACP is insufficient. The following paragraphs review the relevant literature.

One study that examined the role of interpersonal factors in Muslim Americans’ engagement in ACP was Rahemi’s (2017) cross-sectional study, which was discussed under the intrapersonal factors. The researcher examined the relationship between attitudes toward ACP and two interpersonal factors, acculturation, and social support. While social support had no significant correlation with attitudes toward ACP, acculturation positively associated with attitudes toward ACP ($r = 0.42$).

Social ties may play a role in the Muslim Americans preferences related to the end of life. Rahemi et al. (2019) who explored the EOL preferences among 125 Iranian Americans (86% were Muslims) found that the majority (84.8%) preferred hospitals to homes as the place of receiving the EOL care. The number of people living in the house and social support significantly influenced the selection of the site of receiving the EOL care. Specifically, per one additional person living at home, there was a 40% increase in the likelihood of selecting home. Per one extra point in social support, there was a 17% increase in the probability of choosing home as a preferred place to receive the EOL care.

As a summary, research that has examined the influence of interpersonal factors on ACP engagement among Muslims living in the United States is minimal. However, the research that has examined the impact of the interpersonal factors on ACP engagement among community-dwelling adults has focused on two contributing factors.
The first interpersonal factor was social support. Social groups may serve as a healthcare proxy, participate in ACP formal and informal conversations, encourage the loved ones to participate in ACP. Although some studies found that social support was associated with a higher quality of EOL care and greater ACP engagement, some studies observed no or negative association. Acculturation is the second interpersonal factor that has been examined for its effect on ACP engagement. Overall, evidence showed that with greater acculturation, the likelihood of participation in ACP surges up. Also, acculturation was associated with better awareness of, knowledge about, and attitudes towards ACP.

**Community Factors**

“Community factors” is the third and the last level of influence that used from the Social Ecological Model (SEM) to describe the behavior of engagement in ACP among Muslims living in the United States. While a variety of definitions have been suggested to define the concept “community,” this study used the concept “community” to refer to “face-to-face primary groups to which individuals belong” (McLeroy et al., 1988, p. 363). Community as a concept is a key concept in Islam. Muslims used the term “Ummah” to refer to the Muslim community. The term Ummah is “expressing the essential unity and theoretical equality of Muslims from diverse cultural and geographical settings” (Oxford Islamic Studies Online, n.d.). Therefore, based on the SEM perspective, Muslim Americans’ behaviors may be influenced by or influence the faith community which they belong. Accordingly, the community factors in this study are those Muslim community-related factors that play key roles in Muslim Americans’ behavior of engagement in ACP.
Community Norms

The first community factor that plays a role in engagement in ACP is “community norms.” According to the Centers for Disease Control and Prevention (CDC) norms are “the actual values, beliefs, attitudes or behaviors shared by most members of a group” (CDC, 2014b, p. 4). Based on the literature, formation, and communication of the community norms are among the primary factors that inform treatment preferences that an individual may choose in the process of ACP (Choi et al., 2018; Mead et al., 2013). This evidence has emerged from research conducted on a variety of ethnic populations. The following paragraphs discuss the main findings from the literature regarding community cultural factors that influence engagement in ACP.

One of the community norms that may influence engagement in ACP is the acceptance of talking about the EOL and death. In some societies, discussing topics related to death and dying is culturally unacceptable and avoidable. This view was observed in the African American, Korean Americans, Chinese, and Russian communities. In a randomized cross-sectional study included 205 older American adults (110 African Americans and 95 Whites), African Americans held a belief that hindered their engagement in ACP. In particular, the researchers observed that African Americans were less likely than their Caucasian counterparts to feel comfortable when talking about dying and ACP (Johnson et al., 2008). This norm was also held by Taiwanese, Chinese, Korean adults as well (Glass et al., 2010; Yap et al., 2018). Thus, older Korean Americans and their family caregivers were avoiding family conversations about death and dying including ACP (Kwak & Salmon, 2007). Russian immigrants have a similar
view. Eckemoff and colleagues (2018) found that Russian immigrants believed that talking about death is taboo and unwelcomed within the Russian community. Therefore, ACP conversations should be avoided unless imminent death is close (Eckemoff et al., 2018). One Russian immigrant family caregiver said,

> I don’t think Russians really discuss those matters, it’s like . . . something in the future and you don’t really talk about this . . . I don’t see an easy way to start talking about that because if I say, ‘So, Mom what do you want to do when you have six months left?’ . . . then she will be, “Are you already ready to bury me?” (Eckemoff et al., 2018, p. 237)

Another community norm may play a role in engagement in ACP is the community view about ACP. As discussed early in this chapter, evidence has supported that holding positive views about ACP leads to a higher chance of engagement in it (Ko & Lee, 2014; McAfee et al., 2019). The research found negative views toward ACP held by some racial minority such as African American, and Asians communities. African Americans were more likely than Whites to hold a belief that ACP is against God’s will (Johnson et al., 2008; Ramsey, 2013). For example, Bullock (2011) conducted a qualitative study used focus group method to explore 202 American older adults’ (>55 years) views regarding ACP. Most of the White older adults sated positive comments about the benefits of ACP such as “wanting to make sure family members knew their wishes” and not wanting other people to make medical decisions for them.” Whereas, African Americans were more likely to say negative comments about ACP such as “I don't think it would help at all” and/or “there is really no need to talk about it or plan for it” (Bullock, 2011, p. 9). Further, Whites viewed ACP as a facilitator of self-
determination and communication with healthcare providers whom they trusted. In contrast, most of African American participants reported a mistrust with the healthcare system and preferred family members to participate in making decisions regarding health. Additionally, African Americans held unfavorable views regarding ACP. Thus, some of them believed that ACP gives healthcare providers the full authority to remove or deny medical treatments regardless of one’s preferences (Bullock, 2011).

Asians immigrants held similarly negative views about ACP. Majority of Asians who were living in the UK believed that ACP would never add any improvement in the quality of death (Musa et al., 2015). Consistently, a qualitative study, that included 20 older Korean American adults and 16 family caregivers, found that the participants who were reluctant to complete an AD had a belief that that legal forms would never be modified in the future, and therefore they would be stuck with the decisions that they made regarding healthcare (Kwak & Salmon, 2007). Moreover, some young adult Americans held such negative views regarding ACP. Therefore, the main cited reasons for unwillingness to engage in ACP were: “Don’t want to think about death and dying” (90%); “The topic is too depressing” (70%), and “Too many other things to worry about right now” (56%) (Tripken & Elrod, 2018, p. 632).

**Communication and Decision-Making Styles**

The best way of communication of the EOL treatment preferences varies among communities. Unlike the majority of Americans who prefer clear, direct contact some minority cultures prefer indirect one. For example, older Korean American adults felt that their loved ones are aware of their preferences regarding EOL treatments without holding
face to face conversations. The same view was also shared by their caregivers who reported that they indirectly knew what their parents prefer based on their life philosophy or shared thoughts about other relatives’ death. Here two quotations highlighted this view (older adult): “My children already know what I want, so why talk about it and cause [emotional] troubles?” The caregiver’s mother said, “She is likely to want everything done for her . . . I know my mother’s personality and how she is” (Kwak & Salmon, 2007, p. 1870). The similar findings shared by a qualitative study that included 14 Chinese American older adults, and nine family caregivers. In particular, older adults reported that they avoid ACP conversations with healthcare provider unless these discussions initiated by them. Consistently, family caregivers were reluctant to begin such talks with their parents, and they prefer that dialogue to be undertaken by health care providers (Chi, Cataldo, Ho, & Rehm, 2018).

In this vein, Radhakrishnan and colleagues (2017) conducted descriptive qualitative research involved 36 South Asian Indian-American older adults, ten family caregivers, and four healthcare providers to explore factors that affect engagement in ACP. The focus group interviews revealed many factors that may contribute to a lack of engagement in ACP such as inadequate knowledge about ACP, and absence of discussions about ACP initiated by healthcare providers. Also, participants reported the communication style might hinder ACP discussions. Specifically, some participants argued that Asian people are hesitant to disclose their concerns and feelings which might decrease the likelihood of initiating ACP conversations. For example, one healthcare provider said “our culture is, if I have a problem, I need to figure it out. Let's keep it
under the rug. I'll find some solutions, but I don't want to talk about it. We came from the society we never talked about anything” (Radhakrishnan, Saxena, Jillapalli, Jang & Kim, 2017).

Decision-making style is a significant aspect of interest within the literature of ACP. While some communities favor that each person makes his own health-related decisions, others favor family-centered decision-making one (Back & Huak, 2005; Bullock, 2011). Unlike family-centered decision-making approach, autonomy approach associated with more engagement in ACP. For example, Kelley and colleagues (2010) found 60% increase in the likelihood of completion of an AD per each one additional point in preferring autonomy score among Latinos (Kelley et al., 2010). Family-centered decision-making approach involves dominant family participation in making decisions related to a loved one’s health (Hong et al., 2018; Mead et al., 2013; van der Steen et al., 2014). The family-centered decision-making approach seems to be highly valued among racial minority groups living in the United States (Mead et al., 2013). While Caucasian older adults preferred to make their own health-related decisions, African American ones favored their family to participate in making health-related decisions (Bullock, 2011). Hispanic, Hmong and Russian older immigrants believe that it is more culturally appropriate that family members make decisions on behalf of them when they become critically ill (Kwak et al., 2014). Similarly, the majority of Chinese American older adults (55.1%) preferred that their closed ones have the authority to make decisions when they become critically ill (Gao et al., 2015). Further, the majority (64%) of Latino elders agreed with family-centered decision making (Kelley et al., 2010).
Some scholars have suggested that a social value called “familism” can explain the family-centered decision-making style. Familism is “a social pattern in which the family assumes a position of ascendance over individual interests” (Merriam-Webster, 2019). Upon Hispanic people’s perspectives, ACP may view inappropriate because it contradicts *familismo* (familism), which puts the consensus superior over an individual’s decision (McLean, Habicht & Foote, 2016). Also, the effect of familism on ACP engagement was indicated by total dependence on the family to make decisions. The complete reliance on family to make decisions related to a loved one’s health might negatively influence engagement in ACP. In a qualitative study involved 20 Canadian older adults, Taneja et al. (2019) found that participants viewed that ACP is optional because they had a trustful family who can make decisions on behalf of them. Consistent views were reported by Korean older adults (Ko & Berkman, 2012). However, they added that having a healthcare proxy is essential for people who have no families or those who have families but unreliable (Ko & Berkman, 2012).

Filial piety is another unique community value that may inform family-centered decision-making style, mainly among Asian Americans (Korean Americans, Chinese, Taiwanese, and Japanese). Based on filial piety sons and daughters are obligated to provide mutual respect and care for their parents during their lives and pray for them after death. Whereas, parents are compelled to provide compassionate love for their children (Abdullah, Shukri & Othman, 2011; Lee, Hinderer & Kehl, 2014). Kwak and Salmon (2007) argued that filial piety cultural tradition requires family caregivers to make the best decisions regarding EOL treatments on behalf of the terminally ill loved ones.
Therefore, Korean American older adults thought that ACP is unnecessary to be considered (Kwak & Salmon, 2007). Likewise, filial piety was cited as a barrier of ACP engagement in South Asian Indian-American community (Radhakrishnan et al., 2017).

**Community Factors among Muslims**

As one community, Muslims are required to follow the Islamic law which informs all of the life aspects including physical, psychosocial, financial, and spiritual ones (Malek, Rahman, Hasan & Abdullah, 2018). Thus, Muslims are supposed to follow Islamic law when they are considering engagement in ACP. The Islamic law is stemmed from two primary sources: (1) the holy book “Qur’an” and (2) Sunnah or Hadith. The Qur’an is “a compilation of revelations, from Allah, whereas the Hadith consists of the recorded sayings, actions and tacit approvals of Prophet Mohammad” (Abdullah et al., 2011, p. 136). If there is no clear religious opinion about a living matter in the two mentioned sources, Muslims may consult Islamic Jurists (Imams), who may give religious opinions about matters and concerns “Fatwa” based on religious education that they must have to become imams (Clarfield, Gordon, Markwell & Alibhai, 2003).

Islamic law teaches Muslims that talking about death is not a taboo (Sheikh, 1998). Allah (God) said in the Qur’an “Every soul shall have a taste of death: In the end to us shall you be brought back” (29:57). Therefore, Islam teaches Muslims to recall and predict death at any time (Sarhill, LeGrand, Islambouli, Davis & Walsh, 2001). Though, Islam stresses that one’s life is sacred trust from Allah (God) and must be saved (Sheikh, 1998). However, what is the current Muslim American community norm regarding
holding conversations about death and dying has not been highly considered in the literature.

In the Muslim community, the term “will” or “Al-wasiyah” in Arabic, has been an important concept since the seventh century; however, it differs from the term “living will” that is used these days (Al-Jahdali, Baharoon, Al Sayyari & Al-Ahmad, 2013). In particular, the term “will,” includes “detailed instruction on inheritance, guardianship, and burial issues” and becomes active after the death (Al-Jahdali et al., 2013, p. 166).

Based on the Qur’an, completing a personal will is highly recommended for each Muslim. Therefore, in the Qur’an, Allah (God) says “If one of you facing death can leave a legacy, he should bequeath “leave” it to his parents and relatives, according to the law. This is the duty of the pious” (Qur’an 2.180).

Islamic teachings seem to be consistent with the self-determination principle of the ACP (Al-Jahdali et al., 2013; Islamic Medical Association of North America [IMANA], 2005). A story that happened in the era of the Prophet Mohammad indicates the importance of considering ACP for the end of life. According to Al-Jahdali et al. (2013), the Prophet (PBUH) “asked not to be given medications during his illness in view of the fact that his death was imminent and that the treatment was futile. In one of the episodes when he became temporarily unconscious in his final illness the companions, out of love for the Prophet, tried to force feed the medicines. When the Prophet regained consciousness, he was not happy about this and reprimanded the persons responsible for this act” (Al-Jahdali et al., 2013, p. 167).
Based on this story Al-Jahdali et al. (2013) concluded that what happened to the Prophet Mohammad (PBUH) near his death is evidence of his agreement with ACP. Thus, they observed that this story indicates two main things related to ACP: (1) when death is imminent, people have the right to self-determination and refusing treatments, and (2) coercion to have a particular treatment is prohibited and coercing people are accountable for such actions. Similarly, the IMANA agrees with ACP and recommends that all Muslims have a “living will”, an “advance directive” and a “case manager” for their care, to help physicians to know their wishes, when he or she is unable to give directions (IMANA Ethics Committee, 2005, p. 37).

Unlike the American norm of individualism and self-determination, Muslims usually define themselves as a relative part of their families (Hammoud, White & Fetters, 2005; Moazam, 2000). Family-centered decision-making style is followed by Muslims worldwide (Beaty, 2015; Da Costa et al., 2002; Moazam, 2000). Thus, the whole family including the first-degree relatives and grandparents may participate actively in the decision-making process (Beaty, 2015; Da Costa et al., 2002; Moazam, 2000; Al-Shahri, 2002). However, there is limited evidence about how decisions are made at the Muslim American family-level and how this might influence engagement in ACP.

Although the Islamic law agrees with holding conversations about death and dying and engagement in ACP, there is a scarcity of studies considering to what degree the Islamic law and norms have affected Muslims’ engagement in ACP. However, based on the limited published research that has included Muslims living in the United States, the Muslim community norm seems to be not against ACP. One of these studies that
included American Muslim adults was a cross-sectional mixed methods study by Duffy and colleagues (2006). The researchers examined the EOL preferences among American older adults based on ethnicity and gender. Data were obtained using a mixed method including focus group interviews and self-administered questionnaire. While seventy-three people participated in the interviews, 62 of them responded to the survey. The participants were primarily from five racial/faith groups: Arab Muslims, Arab Christians, Hispanics, Blacks, and Whites. While the Arab Muslim participants were against residing a loved one in a nursing home or hospice, voluntary life termination, telling a patient bad news, and artificial life-sustaining treatments, they accepted the idea of completing a will when they become seriously ill (Duffy et al., 2006). Since the number of Muslim participants was low (five women and four men), study findings could not be generalizable for the entire American Muslims community. However, the study findings remain essential because of limited literature about Muslims living in the United States.

To summarize, community factors that influence ACP engagement behavior vary among communities. The research in this area was lack for using theoretical or conceptual frameworks and measurement tools, used qualitative research methodology abundantly, and focused on people from minority groups. Common community factors that have shown to be influential on engagement in ACP have been conceptualized into “community norms,” and “communication and decision-making styles.” Community norms are those views and beliefs that a community holds regarding talking about the end of life, death, and ACP activities. While talking about such issues is a taboo and must be avoided in some communities, it is welcomed in others. Although community norms are
vital for the Muslim community, there is a scarcity of studies considering to what degree the community norms may affect Muslims’ engagement in ACP.

Summary of Current Knowledge

This literature review discusses the studies that have addressed ACP engagement among the community-dwelling adult population. Through the lens of the Social Ecological Model (SEM), intrapersonal, interpersonal, and community factors that influence engagement in ACP have been conceptualized and discussed. The following paragraphs review the main findings of this literature review.

Many intrapersonal, interpersonal, and community factors influence people’s engagement in ACP. The most common intrapersonal factors cited in the literature were demographic characteristics, socioeconomic and health status, EOL experience, knowledge about ACP, and attitudes toward ACP. Although social support and acculturation were influential interpersonal factors, community norms, and communication and decision-making styles were found to be the most common community factors that influence ACP engagement behavior.

Overall, the literature synthesis indicates that the following factors increase the prevalence and the likelihood of engagement in ACP: older age, female gender, greater income, higher education, poor health status, greater number of chronic diseases, positive history of receiving medical treatment that provided for terminally-ill persons, experience of loss, having awareness of ACP, having knowledge about ACP, holding positive attitudes toward ACP, being socially supported, greater acculturation, holding supportive
beliefs for ACP, adopting a direct approach of communication, and expressing higher autonomy in decision-making.

While older adults reported greater engagement in all of ACP activities, their younger counterparts were more likely to engage in informal ACP than more formal conversations or the completion of ADs. Being a female predicted a higher likelihood of having ADs than being a male. Unlike age and gender, marital status showed inconsistent association with ACP engagement. The disparity among racial groups was presented in many ACP activities. The number of non-curable illnesses, history of receiving the EOL treatments, or experiencing a loss of loved one were positively associated with engagement in ACP activities. Lack of awareness of and knowledge about ACP was dominant among racial and ethnic minorities and could lead to greater disparity in ACP engagement. Holding positive attitudes toward ADs is one of the most significant factors that predict completion of ADs.

Social support and acculturation were two main interpersonal factors that influence ACP engagement among community-dwelling adults. Social network participation in ACP is existing mainly in informal ACP discussions and substitute decision-making. Social support has been a critical supportive resource for people to engage in ACP. However, some studies observed no or negative association between social support and engagement in ACP. That vast majority of the studies noted that greater acculturation was incorporated with better engagement in, and knowledge about ACP.
One of the community norms that may influence engagement in ACP is the acceptance of talking about the EOL topics and death. In some societies, discussing issues related to death and dying is culturally unacceptable and avoidable. Also, some racial minority held negative views toward ACP that may affect their participation in ACP such as ACP is God’s will, the uselessness of the ACP, and ACP gives healthcare providers the full authority to remove or deny medical treatments regardless of one’s preferences. Variation in the communication and decision-making styles might contribute to the disparity in ACP engagement among people from different communities. Thus, using indirect communication, and family-centered decision-making style were ACP engagement barriers.

Islamic teachings seem to agree with ACP and accept conversation about death and dying. Also, based on the limited published research that has included Muslims living in the United States, attitudes toward ACP, and having experience of loss of a loved one were the only two intrapersonal factors that were associated with engagement in the EOL planning among Muslims population living in the United States. Age, gender, spirituality, and healthcare insurance status were not associated with engagement in the EOL planning. Attitudes toward the EOL planning demonstrated positive associations with acculturation and healthcare system distrust, but a negative association with spirituality and no relationship with social support.

Knowledge Gaps

This review of the literature has highlighted several gaps in knowledge about ACP engagement behavior. One of these gaps is that most studies that have addressed
ACP engagement behavior have focused only on older adults, and there is a little discussion about ACP engagement among healthy young adults. According to Schnur and Radhakrishnan (2019), there were only three published studies that have examined ACP engagement among healthy young adults. Therefore, little is known about ACP engagement behavior and its contributing factors among young adults. By including community-dwelling adults who are 18 years or older, this study contributes to fill this gap and broadens knowledge in this area.

Being a female was associated with greater awareness and engagement in ACP. However, it is not clear what the contributing factors are related to such gender-related difference in engagement in ACP. Associations between marital status and other variables related to ACP such as ACP engagement, knowledge of, and attitudes toward ACP were minimally examined in the literature. Also, there was no consensus in the literature about the presence of associations between marital status and ACP engagement, knowledge of, and attitudes toward ACP engagement. This study contributes to the current knowledge by adding information about the associations between marital status and engagement in ACP.

While primary research examining ACP among racial minority groups is abundant in the literature, little research has been conducted addressing ACP topics among minor faith communities in the United States. Although the disparity in ACP engagement in ACP activities exists among racial groups, there are differing findings in the literature about whether or not race can predict differences in ACP engagement. Also, limited research has examined the combined effect of the contextual and environmental
factors on explaining the disparity in ACP. This study contributes to current knowledge of ACP engagement behavior by examining the combined influence of a variety of contextual factors (intrapersonal, interpersonal, and community factors) on ACP engagement behavior among a minority faith community living in the United States.

Although knowledge about, and attitudes toward ACP are critical interpersonal factors that affect ACP engagement, this review found several gaps in the literature regarding these factors. The first gap is evident by a lack of research investigating knowledge about and attitudes toward ACP among healthy populations, including young adults. The second gap is a lack of studies that used reliable and valid tools that measure knowledge about and attitudes toward ACP. The final gap is a scarcity of research that has assessed Muslims’ awareness and knowledge about, and attitudes toward ACP. This study contributes to addressing this gap by measuring awareness of, knowledge about, and attitudes toward ACP within a sample of community-dwelling Muslim adults, including young adults and using reliable and valid instruments.

The vast majority of the published research in ACP to date has tended to limit the assessment of ACP engagement behavior to three or fewer ACP activities, including the completion of an AD (living will and healthcare proxy) and holding an informal conversation. This study considered ACP as a multi-activity behavior including: (1) completion of an ACP formal document, (2) designation of a health care proxy, (3) discussion of medical treatment preferences with family members, and (4) discussion of medical treatment preferences with healthcare providers. Through this approach, this
study contributes to current knowledge by providing information about other ACP activities that has been studied on a limited basis.

Although there were two studies (Rahemi, 2017; Rahemi et al, 2019) that examined the association between ACP and some of the intrapersonal and interpersonal factors among Muslims living in the United States, these studies had many limitations that might limit the generalizability and left many gaps in current knowledge that needed to be addressed. The first limitation is that the two studies were structured to examine the construct “end of life planning,” which might conceptually and operationally differ from ACP. Second, the two studies intended to examine Iranian American population, which has diverse faith communities. Therefore, the findings might not reflect the perspective of Muslims. Third, the two studies measured EOL planning by a single item rather than using multi-items tool that address multiple ACP activities. Fourth, the two studies included only adults who were 50 years or older. Thus, young adults were not studied. Fifth, Rahemi (2017) explored associations between a set of contextual factors and “attitudes toward end of life planning” rather than “end of life planning. Although “attitudes toward end of life planning” was the outcome variable of Rahemi’s (2017) study, participants’ attitudes toward ACP were not described. Therefore, attitudes toward ACP of the Muslims living in the United States was not described. The intent of this current study was to examine strategies that mitigate such limitations and then contribute to fill gaps in current knowledge. Therefore, this study was conceptually structured to examine the construct “ACP engagement.” This study used structured tools to measure
the study constructs, including Muslim adults, regardless of their age, and described participants’ attitudes toward ACP along with other contextual factors.
CHAPTER III
METHODOLOGY

The current study focused on understanding the behavior of advance care planning (ACP) engagement among adult Muslims who were living in the United States. This chapter provides a detailed description of the study design, settings, participants, instruments, procedures, data analyses, and human subjects protection.

Design

A cross-sectional, correlational design was used to describe the behavior of ACP engagement among Muslims living in the United States. This design allowed examination of the potential associations between the behavior of ACP engagement and a set of variables that have been chosen based on the Social Ecological Model (SEM) and the review of the literature (Hulley et al., 2016). Since the proposed research aimed to explore a phenomenon that has not been well studied, the proposed design helped was intended to learn the current status of the phenomenon within a relatively short period of time (Gliner, Morgan & Leech, 2017).

Setting

The recruitment of this study was in North Carolina (NC), which is one of the Southeastern states in the United States. Large Islamic organizations in four NC counties, including the Piedmont Triad and Triangle mid-state regions, were selected as recruitment sites. The large Islamic organizations included Islamic centers, mosques,
clinics, halal grocery stores, halal restaurants, and student associations. These sites were approached because they were primarily serving various age groups of Muslims living in the United States. Choosing these sites helped to reach a heterogeneous sample of the Muslim population.

**Sample**

This study included a sample of adults who self-identified as Muslims living in the United States. Any adult was able to participate in this study if he or she met the following inclusion criteria: (1) self-identified as a Muslim, (2) lived in the United States for at least one year at the time of recruitment, (3) was 18 years old or older, and (4) was able to read, write, and comprehend English. However, any participant was excluded if he or she was younger than 18 years old, was non-Muslim, lived in the United States for less than one year, or was unable to read, write, and comprehend English. Based on G*Power calculations of linear regression, a sample size of 122 was determined to provide a statistical power of $\geq 80\%$, assuming a type I error rate of 0.05, an effect size of Cohen’s $f^2 = 0.15$, and 5% of data missing (G*Power version 3.1.9.3).

**Recruitment**

Since Muslims living in the United States are a minority religious group, both convenience and snowball sampling were used concurrently to obtain the required sample. Involvement of Muslim community insiders and key persons of Islamic organizations in recruitment has been one of the effective tactics that have improved Muslim minority group participation in research (Mohammadi, Jones & Evans, 2008). Thus, the principal investigator (PI) contacted the community insiders and key persons in
the recruitment sites to assist in recruiting participants. The PI, with community insiders’ assistance, distributed the study flyer at the sites. The community insiders were encouraged to share the link of the online survey (Qualtrics) with their community members through their communication channels, including social media platforms. The flyer briefly displayed the purpose of the study and provided the researcher’s name and contact information. Also, the PI announced the study at the proposed recruitment sites and posted and distributed the study flyer.

Therefore, at that point, each location was able to distribute the online survey link and the electronic version of the flyer through various communication methods, such as emails, text messages, and social media platforms. Both printed and electronic versions of the study flyer included a mobile phone scannable QR-code, and a link to the online survey. Any individual who scanned the QR-code or clicked the link received access to read the information sheet and to complete the study questionnaire. Printed copies of the survey were made available for participants who preferred completing the printed version. Those who preferred to complete the paper-based questionnaire were given the opportunity to do so at a location of their choice or at the recruitment sites in a private and safe place that was predetermined collaboratively with each recruitment site administrator. Each participant who chose to respond later received a printed copy of the questionnaire as well as a stamped addressed envelope to facilitate returning it back to the researcher’s physical address. Although the survey was self-administered, the PI provided help for those who required assistance.
Measures

A structured, self-reported questionnaire was used to collect the data. Because there are multiple native dialects used by Muslims living in the United States, the study questionnaire was provided only in English, which is the most used dialect in the United States. The study questionnaire consisted of items that operationally assessed the study outcome construct (ACP engagement) as well as the constructs of the three levels of SEM (intrapersonal, interpersonal, and community factors). The following paragraphs discuss the tools that were used to measure the study constructs, including five intrapersonal factors, two interpersonal factors and two community factors. The factors included ACP engagement, demographic characteristics, socioeconomic status, health status and past end of life medical treatment experiences, ACP knowledge, attitudes toward ACP, social support, acculturation, community norms, and decision-making style.

Outcome (ACP Engagement)

The primary outcome variable in this study was ACP engagement. The four-item version of the Advance Care Planning Engagement Survey (ACPES-4) was used to measure ACP engagement. The scale is a theory-driven scale developed by Sudore, Heyland, Barnes, et al. (2017) to measure older adults’ engagement in different ACP activities. The activities include designate health care proxy, communicate medical treatment preferences with a healthcare proxy, communicate medical treatment preferences with a healthcare provider, and complete an official document reporting medical treatment preferences (Sudore, Heyland, Barnes, et al., 2017). A 5-point response scale ranging from 1 = “I have never thought about it” to 5 = “I have already
done it” was used to rate responses. The overall average score of ACPES-4 could range from 1-5, with a higher average score indicating a greater engagement in ACP. An additional question asking about the time of action was added for those who would choose “5 = I have already done it” to assess the stage of change of ACP engagement behavior (action vs. maintenance). While engagement in an ACP activity within six months was ordered in the “action” stage, engagement for at least six months was ordered in the “maintenance” stage for that activity. Internal consistency reliability of the ACPES-4 was adequate, with Cronbach’s alpha coefficient at 0.86 (Sudore, Heyland, Barnes, et al., 2017). Both face and construct validity were appropriately established (Sudore, Heyland, Barnes, et al., 2017). Although the ACPES-4 has been used recently in a pilot study that examined the effect of ACP educational program on ACP engagement among 27 patients and family caregivers, internal consistency reliability was not estimated in that study (Rabow, McGowan, Small, Keyssar & Rugo, 2019). Cronbach’s alpha coefficient in this study was 0.89.

**Intrapersonal Factors**

**Demographic Characteristics**

A set of demographic characteristics were assessed in this study to reflect part of the intrapersonal construct. Age was measured in years. Respondents could choose male or female to identify gender. Five options were provided to indicate marital status. To assess race, respondents self-identified their race by selecting from several options provided. Questions that assess other demographic characteristics such as place of living,
length of living in the United States, country of origin, and the native language were included in the questionnaire.

**Socioeconomic Status**

In this study, the socioeconomic status referred to “a composite measure that typically incorporates economic, social, and work status” (Centers for Disease Control and Prevention (CDC), 2014a). Social status was measured by the level of education that could be selected from several options. The economic status was assessed by indicating the annual household income. Work status was assessed by asking whether a person had a job or not, and what type of job that they reported.

**Health Status and Past Experiences**

Health status was assessed with a single-item global self-rated health, which rated health as poor, fair, good, very good, or excellent (CDC, n.d., Idler & Benyamini, 1997). Past end of life treatment experience was assessed by six dichotomous yes-no questions (Amjad et al., 2014). Sample questions were: (1) “have you had a serious illness before,” and (2) “do you know anyone who declares to others (family, friends, healthcare provider) his preferences before he died.”

**Knowledge about Advance Care Planning**

Knowledge about ACP was assessed by using a six-item subscale adopted from Advance Care Planning Engagement Survey (ACPES) (Sudore et al., 2013). The ACPES is a four-subscale tool that measures four domains of engagement in ACP, which are Decision-Making, Quality of Life, Flexibility, and Ask Questions. The knowledge subscale consisted of six items, with five-point rating scale range from “Not at all” to
“Extremely.” The subscale of knowledge showed a satisfactory reliability measure (Sudore et al., 2013). The internal consistency reliability of the subscale was excellent in a previous study with a Cronbach’s alpha coefficient of 0.84 (Sudore et al., 2013). Also, the one-week test-retest intraclass correlation was 0.70 (Sudore et al., 2013).

Discriminant validity was calculated for the total scale (Advance Care Planning Engagement Survey) by comparing scores between the primary participants (50 older adults) and 20 healthy community-dwelling young adults. Sample items are “how well informed are you about who can be a medical decision maker?” and “how well informed are you about the types of questions you can ask your doctor that will help you make a good medical decision?” The average total knowledge score ranges from 1-5. The higher average rating indicates better knowledge about ACP. The instrument has been used in ACP research (Sudore, Boscardin, et al., 2017; Sudore, Casarett, et al., 2014; Van Scoy et al., 2017). However, internal reliability was not estimated in the latter studies.

Cronbach’s alpha coefficient was calculated in this study as $\alpha = 0.95$.

**Attitudes toward ACP**

In this study, the construct “attitudes” referred to “a disposition towards or against the specified phenomenon, person or thing” (Dawson, 1992, p. 473). Attitudes toward ACP was measured by a tool developed by Fried et al. (2012) to primarily measure decisional balance. The tool is a 12-item (six items are pros and the other six are cons) scale rated by a 5-point response scale, ranges from 1 = “not at all important” to 5 = “extremely important.” Examples of items are “doing advance care planning would simplify how decisions would be made if I were very ill,” and “it would be hard to do
advance care planning because I don’t like thinking about being very ill.” Internal reliability testing was performed in a group of 304 older adults, with an estimated value of Cronbach’s alpha coefficient at 0.86 (Fried et al., 2012). The average total score could range from 1 to 5, with a higher average score indicating higher pros or cons of ACP. Although the tool was used in ACP literature, no sufficient information about the new internal reliability estimates was provided (Fried et al., 2016; Fried et al., 2018; Sudore, Casarett, et al., 2014). Cronbach’s alpha coefficients were calculated in the current study, with $\alpha = 0.88$ for pros subscale and $\alpha = 0.85$ for cons subscale.

**Interpersonal Factors**

**Social Support**

Social support was measured by the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988). The MSPSS is 12-item tool measures an individual’s social support received from family (Items 3, 4, 8, and 11), friends (Items 6, 7, 9, and 12), and significant others (Items 1, 2, 5, and 10). The tool items rated on a 7-point Likert type scale that ranges from 1 = very strongly disagree to 7 = very strongly agree. The total score ranges from 12 to 84, with the higher scores indicate greater levels of social support. The total scale found to be valid and reliable (Dahlem, Zimet & Walker, 1991; Zimet, Powell, Farley, Werkman & Berkoff, 1990). Precisely, internal reliability (Cronbach's alpha coefficient) and test-retest reliability were estimated at 0.88, and 0.85, respectively (Zimet et al., 1988). Mean scores of the scale range from 1 to 2.9 indicates low support, from 3 to 5 indicates moderate support, and greater than 5 indicates high support (Zimet et al., 1988; Zimet et al., 1990). The tool has
been widely used transculturally among Muslims including those living in the United States (Aroian, Hough, Templin, Kulwicki, Ramaswamy & Katz, 2009; Azim & Islam, 2018; Moh'd Yehia, Callister & Hamdan-Mansour, 2013; Ramaswamy, Aroian & Templin, 2009). Cronbach's alpha coefficient was calculated as $\alpha = 0.94$ in this study.

**Acculturation**

The construct “acculturation” “comprehends those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original cultural patterns of either or both groups” (Redfield et al., 1936, p. 149) To measure this construct, the Acculturation Scale for Muslim Americans (ASMA) was used. The ASMA was primarily created to assess the degree of a Muslim adult’s advocate for Islamic values and beliefs in addition to the degree of integration in the American culture (Bagasra & Mackinem, 2019). The tool consists of 13 items divided into two subscales. A five-point response scale, ranging from 1 = “not true at all” to 5 = “extremely true” is used to rate each item. The first subscale, Adherence to Islamic Identity Subscale (AIIS), consists of 5 items measuring a person’s Islamic identity. The total score of Adherence to Islamic Identity Subscale could range from 5 to 25, with a higher score indicating more Islamic cultural identity. The second subscale, which is called Conformity to American Norms Subscale (CANS), has eight items that measure how much a Muslim person is adopting the American culture. The total score of Conformity to American Norms Subscale could range from 8 to 40, with a higher score indicating more adaptation of the American culture. The ASMA psychometric analysis showed adequate face validity and internal consistency reliability
for both subscales, with Cronbach’s alpha coefficients of 0.72, and 0.79, respectively (Bagasra & Mackinem, 2019). Sample items include “It is important to me to wear clothing that reflects my Muslim identity,” and “I would be willing to marry a non-Muslim.” there are additional published studies that have used the ASMA. In the current study, Cronbach’s alpha coefficients were calculated as $\alpha = 0.69$ for AIIS, and as $\alpha = 0.82$ for CANS.

**Community Factors**

**Community Norms**

The “community norms” is defined as “the actual values, beliefs, attitudes or behaviors shared by most members of a group” (CDC, 2014, p. 4). Operationally, “community norms” that may influence ACP engagement were measured by the ACP Values/Belief scale developed by Fried et al. (2012). The tool consists of 7 items rated by a 5-point Likert scale, ranging from 1 = “strongly agree” to 5 = “strongly disagree.” Sample items include “if you fill out a document such as a living will, the doctors are more likely to “pull the plug” soon,” “there is no need for me to do advance care planning because once you reach a certain age, the doctors aren’t going to use machines,” and “advance care planning would interfere with the plans that the Lord has for me.” The average total score could range from 1 to 5, with higher average score indicating more positive values and beliefs toward ACP. Internal consistency reliability was estimated by Cronbach’s alpha coefficient, with $\alpha = 0.89$ (Fried et al., 2012). No information was provided about reliability estimations in a later study that used the tool (Sudore, Casarett, et al., 2014). In this study, Cronbach’s alpha coefficient was estimated as $\alpha = 0.83$. 
**Decision-Making Style**

Decision-making style was defined in this study as Muslim people’s preferences regarding decision making style. The Control Preferences Scale (CPS) was used to measure the preferred decision-making style. The CPS is a one-item question with five response options developed to assess the degree of control that a person prefers to have when participating in medical decision-making (Degner, Sloan & Venkatesh, 1997). The responses could be clustered into three categories of role responses: active (autonomous), collaborative, and passive (Degner, Kristjanson et al., 1997). The question is “How do you prefer to make medical decisions with your doctor?” Sample of responses include “I prefer to make decision about what treatment I will receive,” and “I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.” The CPS has been shown to have good psychometric properties (Degner, Sloan, et al., 1997). Also, the CPS was used widely across the Western countries (Singh et al., 2010).

**Procedure**

The principal investigator (PI) contacted the community leaders at the recruitment sites requesting signatures for letters of support that were submitted to the institutional review board (IRB) of the University of North Carolina at Greensboro (UNCG). The PI explained about the study for the community leaders, including the purpose, procedures, and questionnaire to ensure that no questions were asking about sensitive information. After the IRB approved the study, the PI contacted the community insiders asking to allow and facilitate data collection. The PI, with the community leaders and insiders help,
recruited people directly at the recruitment sites. The PI announced the study at the recruitment sites and distributed the study flyer. Concurrently, the PI encouraged the community insiders at the recommended recruitment sites to announce for the study, distribute the flyer, and share the online survey link and the electronic version of the flyer. Therefore, at that point, each location was able to distribute the online survey link and the electronic version of the flyer through various communication methods such as emails, text messages, and social media platforms. Both printed and electronic versions of the study flyer included a mobile phone scannable QR-code that could be scanned, and a link that could be clicked to get access to the online survey. Thus, an individual who scanned the QR-code or click the link got access to read the information sheet in addition to complete the study questionnaire. Printed copies of the survey were available with the PI for participants who preferred completing the printed version. Those who preferred to fill out the paper-based questionnaire had the opportunity to fill out the questionnaire at a location on their convenience or at the recruitment sites in a private and safe place that was predetermined collaboratively with each recruitment sites’ administrators. Each participant chose to respond later received a printed copy of the questionnaire as well as a stamped envelope to facilitate returning it back to the PI physical address. Although the survey was self-administered, the PI provided help for those who required such assistance as needed.

Data Management

Data were collected using paper-based (printed) or online (Qualtrics) surveys written in English. The online data were downloaded from the Qualtrics software into the
SPSS spreadsheet. The paper-based data were manually added to a separate SPSS spreadsheet and then merged together with the online data in the same SPSS spreadsheet. Data cleaning was started by visual detection of missing information and grouping the responses accordingly. The responses to the questions of study eligibility were inspected. Therefore, one case was eliminated as it indicated a “No” response to the eligibility question that required at least one year of the length of stay in the United States.

Decision rules were made regarding the validity of cases. Thus, any case that was completed within 10 minutes or less or had at least 15% of missing data was considered invalid. Consequently, 132 online responses that were completed in less than 10 minutes, and six responses that had more than 15% of missing information were excluded from the final analysis. One of these cases answered the eligibility questions only. Three of the remaining five respondents, who had more than 15% of missing information, were females and the average age was 31 years. After removing 138 respondents from the total number of online ones (n = 247), a total of 109 online responses remained and were included in the final analysis. Adding this number to the total number of respondents who filled out the printed survey resulted in a final sample size of 148 responses.

Prior to beginning any statistical analysis, the numeric responses obtained were visually inspected and reviewed for unusual information that would indicate the presence of invalid responses—for example, indicating the year of birth date instead of the number of years. Thus, six responses were justified to indicate respondents’ age instead of the birth year. In addition to the inspection of unusual information, outliers and
numbers outside of the expected range were examined as well. However, no extreme outliers were noted.

Independent \( t \)-test and Chi-square test were used to compare the excluded online surveys with the included ones regarding age, gender, place of living, immigrant status, marital status, total household income, age, length of stay in the United States, and race. No significant difference was noted between the two groups regarding all characteristics except for age, and race. Those who were excluded were four years older than those who were not included (35.78 vs. 31.78). Age difference was about four years (\( df = 212, t = 3.2, p = 0.002 \)). The eliminated group of participants had a significantly higher number of Hispanics and African Americans than their counterparts in the included group, but it had significantly fewer White and “Middle Eastern or North African” respondents.

The participants were compared based on the type of surveys completed, online versus paper, by using independent \( t \) test. The findings showed that the participants in the two groups were significantly different in age. The age of participants who completed the paper survey (\( M = 44.79, SD = 15.43 \)) was significantly higher than the age of those who completed the online survey (\( M = 31.84, SD = 9.30 \)). This result could indicate that younger individuals preferred online surveys. The number of females who completed the online surveys was significantly higher than those who completed paper ones (51, 11, respectively). Persons living outside of North Carolina or those who were born in the United States were more likely to complete the online surveys than the printed surveys (41 vs. 0, and 55 vs. 1, respectively).
Data Analysis

The goal of statistical analysis was to explore the associations between the outcome variable (ACP engagement) and the potential predictors. In this study, the data analysis plan was tailored for each research question. The following research questions were addressed in this study:

1. What are the ACP engagement behaviors used by Muslim community-dwelling adults living in the United States?
2. What intrapersonal factors were associated with the ACP engagement among Muslim community-dwelling adults living in the United States?
3. What interpersonal factors were associated with the ACP engagement among Muslim community-dwelling adults living in the United States?
4. What community factors were related to the ACP engagement among Muslim community-dwelling adults living in the United States?
5. What combination of intrapersonal, interpersonal, and community factors were associated with ACP engagement among Muslim community-dwelling adults living in the United States?
6. What were the differences between age and gender groups regarding ACP engagement among Muslim community-dwelling adults living in the United States?

For continuous variables, outliers and normality were examined in univariate analysis using boxplots, Normal Q-Q plots, and Kolmogorov-Smirnov tests. Average scores of ACP engagement, length of time in the United States, attitudes (pros), and
attitudes (cons) were transformed by using natural Log method because the normality was violated. Dummy coding was performed for the nominal variables. Missing data (continuous and categorical) were assessed and decisions for transformation and imputations were completed. In addition, MPlus was used for multiple imputations (Muthen & Muthen, 2011).

To answer the first research question, the following data analysis plan was followed. Descriptive statistics were used to describe the ACP engagement behavior. Frequencies and percentages were used to describe and summarize participants’ self-reported engagement in any of the four ACP activities. Similarly, frequencies and percentages were used to describe and summarize participants’ stage of change of engagement according to all ACP activities.

For the second, third, and fourth research questions, descriptive statistics of frequency and percentage, mean, and standard deviation were used to describe and summarize participants’ demographic characteristics, socioeconomic status, health status and end of life experiences, knowledge, attitudes, social support, acculturation, and community norms. Categorical variables were described and summarized using frequencies and proportions. A central tendency measure (mean) and variability index (standard deviation) were used to describe and summarize continuous variables. Bivariate associations between ACP engagement and contentious variables were assessed by Pearson r test. Bivariate associations between ACP engagement and dichotomous variables were assessed by the point-biserial correlation test.
To examine the influence of intrapersonal, interpersonal, and community factors that are associated with ACP engagement, three separate simultaneous multiple linear regression models were completed. Specifically, the first model was run to model the outcome variable (engagement in ACP) with demographic characteristics; socioeconomic status; health status; and past experience, knowledge, and attitudes. The second model included social support, acculturation, and ACP engagement. The third model included community norms, the preferred decision-making style, and ACP engagement. In these models, indicator variables for the categorical independent variables were used. An additional fourth model that included all intrapersonal, interpersonal, and community factors was computed to find the combined influence of intrapersonal, interpersonal, and community factors on ACP engagement. Regression assumptions were checked with the analysis of residuals.

The final research question (sixth) was answered by using the Mann-Whitney U test. A two-sided p-value $\alpha < 0.05$ was considered to be statistically significant for all analyses here. The Statistical Package for Social Sciences (SPSS) version 26 and Mplus software were used to perform all analyses (IBM Corp., Armonk, NY; Muthen & Muthen, 2011).

**Human Subjects Protection**

Approval for the study was obtained from the Institutional Review Board (IRB) of the University of North Carolina Greensboro (UNCG). An information sheet was attached at the beginning of the questionnaire to explain the nature of the study, directions regarding the survey completion, approximate time needed to fill out the
questionnaire, participants’ rights, potential risks and benefits of participation, and the
PI’s contact information for any inquiries. Participants were informed that their
participation was voluntary, and that they could quit participation at any time without any
penalty. Similarly, the participants were notified that if they had any questions about their
participation in this study, they could contact the IRB or the PI by using the contact
information provided. It was assumed that by completing the questionnaire, participants
indicated voluntary participation in the study as well as their understanding of the
information sheet.

To assure anonymity, no identifying information was collected (the survey
questions contained no identifying information). Each questionnaire (paper-based and
online) was assigned a unique identification number (examples: 001, 002, and 003) for
data management and analysis. All data were coded numerically for each variable and
were retained on a password and firewall-protected personal computer and backed up to
UNCG Box, which is a secure and password-protected server at UNCG. Data collected
from online questionnaires were electronically transferred from Qualtrics survey software
to an SPSS spreadsheet and downloaded to a password and firewall-protected personal
computer and then backed up to UNCG Box. For Qualtrics surveys, the IP address was
turned off. Findings were grouped into summary information. Upon receiving the
completed paper-based questionnaires (mailed or in-person), the PI detached the
incentive forms and placed them in a confidential bin at the UNCG School of Nursing.
The contact information provided to claim a gift card (for those who may complete the
online questionnaire) was not linked back to their contact information.
All data collected in this study were kept confidential. Data obtained from the paper-based questionnaires were entered into an SPSS spreadsheet and stored in the UNCG Box. Data that were collected from online questionnaires were transferred from the Qualtrics survey software to an SPSS spreadsheet that was stored in UNCG Box. Only the PI and the dissertation committee members had access to the stored data.

An incentive of an electronic gift card, a $10 value, were offered as a “thank you” for participation. Participants who completed the paper-based questionnaire were informed to complete a separate form (incentives) and return it to the PI with the completed survey. The form asked for information required to send the gift card (the first name and email address). Upon receiving the questionnaire, the PI used the email addresses provided to send a gift card. Those who chose to complete the online survey were informed with instructions on how to submit their first name and email address to claim their electronic gift card. Therefore, to obtain respondents’ information and keep survey responses anonymous, a link for a separate survey (incentives) was provided for the participants to submit their information that was necessary to claim the electronic gift card. All participants were informed that their contact information provided to claim a gift card was not linked back to their contact information.

**Chapter Summary**

This descriptive correlational study was conducted through recruitment at Islamic large organizations and sites in NC counties. A sample of community-dwelling Muslim adults was recruited using convenience and snowball sampling techniques. Several reliable and valid instruments were used in addition to a socio-demographic form to
measure the study variables. Both online and paper copies of the survey were used for data collection. Descriptive and inferential statistical analyses were performed to answer the proposed research questions. Internal consistency reliability of the instruments was estimated and reported using Cronbach’s alpha coefficient as appropriate. Missing data was managed through standard techniques. Human Subjects protection strategies were implemented.
CHAPTER IV
ADVANCE CARE PLANNING ENGAGEMENT AMONG MUSLIM
COMMUNITY-DWELLING ADULTS LIVING IN THE UNITED STATES OF
AMERICA

Abstract

Background: Advance care planning (ACP) is a cornerstone of self-determination. It frames decision-making types of care provided at the end of life. Despite many national efforts to improve American adults’ engagement in ACP, the prevalence of engagement in ACP is still disappointed. Low prevalence is common among racial and ethnic minority populations, people with lower socioeconomic status, young people, rural residents, or non-English speakers. The Muslim population living in the United States is one of the minority faith communities whose engagement in ACP has been minimally studied. Purpose: The purpose of this study was to explore ACP engagement activities among Muslims living in the United States and to examine whether any ACP engagement differences existed according to age, gender, health condition, and experiences of end of life medical treatments. Methods: A cross-sectional correlational design was used. Participants were recruited from Islamic organizations through convenience and snowball sampling. ACP engagement was measured by four items of Advance Care Planning Engagement Survey (ACPES) provided within a paper and online structured self-reported questionnaires. Results: A racially diverse sample of 148 Muslim adults with ages ranged from 18 to 79 years participated in the study. The average ACPES-4 scores ranged from
1.97 (SD = 1.22) to 2.09 (SD = 1.34). About two-thirds of the participants were in the precontemplation stage. No significant ACP engagement differences were found according to gender and age. However, there were significant differences according to ACP awareness, experiences of illness, surgery, decision-making, or EOL treatment.

**Conclusion:** Disparity in ACP engagement exists among the American Muslim community and needs immediate collaborative interventions by health care providers, policymakers, and researchers.

**Keywords:** advance care planning, end of life, decision-making, race, Muslims, Islam, minority

**Introduction**

End of life (EOL) treatment decisions were historically informal in the United States until the passage of the Patient Self-Determination Act that required healthcare facilities funded by Medicare to provide written documents that exhibit patients’ right to participate in making decisions (Senate Bill 5067, 1990; Paris & O’Connell, 1991). The Institute of Medicine (IOM) emphasized Advance care planning (ACP) as a method that facilitates decision making at EOL of seriously ill Americans (IOM, 2015). Similarly, palliative, hospice, and EOL care organizations have supported ACP for seriously ill people (IOM, 2015; National Coalition for Hospice and Palliative Care, 2018; Periyakoil et al., 2016).

**Advance Care Planning**

Advance care planning is defined as “a process that supports individuals at any age or stage of health in understanding and sharing their personal values, life goals, and
preferences regarding future medical care” (Sudore, Lum, et al., 2017, p. 821). People who practice ACP can explore, discuss, and communicate their values, beliefs, preferences, and wishes that they want to be conserved when they become incapable of communicating (Austin et al., 2015; IOM, 2015; Rietjens et al., 2017). There is no one typical action corresponding to ACP (Fried et al., 2009; Fried et al., 2010; Rietjens et al., 2017). Although ACP related activities vary in the literature, the following are common: (1) execution of a living will, (2) designation of a health care proxy, (3) discussion with family and/ or health care professionals a patient’s preferences regarding life-sustaining medical treatment, (4) discussion with family and/ or health care professional a patient’s preferences regarding quality versus quantity of life (Fried et al., 2010; Fried et al., 2018; Sudore, Heyland, Lum, et al., 2017).

Engagement in ACP activities is recognized as a health behavior in which people can be identified by their stage of change (Fried et al., 2010). As a health behavior, ACP engagement stages of change are: precontemplation, contemplation, preparation, action, and maintenance (Fried et al., 2010; Simons-Morton et al., 2012). While a person who has no interest to engage in ACP would be ordered in the precontemplation stage of change, a person who developed an awareness of the need to engage in ACP would be in the contemplation stage. Those who started planning to engage in ACP within the upcoming time, would be in the preparation stage of change. Actual participation in one of the ACP activities is considered being in the “action” stage if it started within six months, but in the “maintenance” stage if it continued to six months or greater (Freid et al., 2010; Sudore, Heyland, Barnes, et al., 2017).
Although ACP activities involve discussions about EOL issues, there is no specific time for engagement in ACP discussions (Sudore, Lum, et al., 2017). People are encouraged to initiate ACP conversations with their families and healthcare providers at any stage of their lives, not just at the EOL stage. Similarly, it is recommended that all adults should be engaged in ACP conversations, regardless of their age, gender, race, or health status (IOM, 2015; Sudore, Lum, et al., 2017). However, a meta-analysis of findings published from 2011 to 2016 has estimated the ACP engagement rate among community-dwelling American adults at 36.7% (Yadav et al., 2017). Disparities in the ACP engagement rate exist, with a low rate of engagement among racial and ethnic minority populations, people with lower socioeconomic status, young people, rural residents, or non-English speakers (Barwise et al., 2016; Harrison et al., 2016; McAfee et al., 2017; Rao et al., 2014; Smith, 2008; Sudore et al., 2018; Yadav et al., 2017). Indeed, the existing evidence on ACP disparities has revealed significant variation in the quality of EOL care and death across all the groups (IOM, 2015).

Age and gender differences in ACP engagement were investigated in ACP literature. Several national reports and studies have noted that the prevalence of engagement in ACP increases with older age (Choi et al., 2018; McAfee et al., 2019). However, there has been a little exploration of ACP engagement among healthy young adults. As of 2019, only a few published studies that examined ACP engagement among healthy young adults were found in the literature (Schnur & Radhakrishnan, 2019). About only 2% of young American adults reported having an advance directive (AD) (Kavalieratos et al., 2015; Schnur & Radhakrishnan, 2019). Results about gender
differences in ACP engagement are inconsistent. Several studies found that women were significantly more likely to engage in an ACP activity than men (Alano et al., 2010; Choi et al., 2018; Dobbs et al., 2015; Rao et al., 2014; Teixeira et al., 2015), whereas other studies found no significant ACP engagement differences between men and women (Carr, 2012; Ramsey, 2013; Schnur & Radhakrishnan, 2019).

Health status and decision-making and EOL experiences play a critical role in engagement in ACP. Overall, poor health status and having a past self-experience of EOL treatments were associated with higher engagement in ACP (Amjad, Towle & Fried, 2014; Carr, 2012; Gao et al., 2015; Moorman & Inoue, 2013; Musa et al., 2015). Similarly, people whose parents had engaged in any of ACP activity were more likely to engage in ACP (Woosley et al., 2017).

**Muslims Living in the United States and Advance Care Planning**

One of the minor faith communities in the United States is the community of the followers of Islam, or Muslim Americans (Clark, 2010). The estimated number of Muslim Americans in the United States varies based on national reports. However, according to the Pew Research Center, there are 3.45 million Muslims in the United States, forming 1.1% of the total population (Pew Research Center, 2018a). The majority of Muslim Americans (58%) are immigrants with a variety of racial and ethnic backgrounds, languages, and national origins (CAIR, 2012; Pew Research Center, 2017; Pew Research Center, 2018b). While the majority (41%) of Muslims living in the United States self-identify as White, approximately one quarter (28%) are Asian, and one-fifth are Black, with roughly half of Muslim Blacks converted to Islam (Pew Research Center,
2018b; Pew Research, 2019). However, there is a shared unified religion that informs life affairs, belief systems, and behaviors among these people (Pew Research center, 2018b). The Muslim American community has the youngest median age (24 years) in the United States (Pew Research center, 2015). However, it has been projected that by 2030 the number of Muslim American seniors, age 60 years or older, will increase from 140,000 to 570,000, which implies a growing need for Muslim Americans to engage in ACP (Pew Research Center, 2015).

The engagement in ACP by Muslims living in the United States has been minimally studied. Thus, it is important to better understand ACP among Muslim adults living in the United States to assist this minor growing segment of the population in patient-centered health care as well as to expand efforts to improve well-being and to add new knowledge about this ethnically diverse population. The purpose of this study was to explore ACP engagement activities among Muslims living in the United States and to examine whether health status and experiences with end-of-life medical treatments and decision-making are associated with engagement in ACP activities. Two research questions were proposed in this study: (1) What is the ACP engagement among Muslims living in the United States?, (2) What are the differences in engagement in ACP activities between participants according to age, gender, health status, and experiences of decision-making and EOL medical treatments?

**Conceptual Framework**

In order to describe ACP engagement according to different stages, this study used the stage of change of the Trans-Theoretical Model of change (TTM) (Prochaska &
DiClemente, 1994). The TTM posits that people transit through a stepladder process of five stages in order to change a current behavior or adopt a new one (Prochaska & DiClemente, 1994). “Precontemplation” is the first stage of change that indicates the absence of interest in doing a behavior. In the second stage, “contemplation,” people develop awareness to change a behavior or adopt a new one. “Preparation” is the next stage, in which a person has a plan to modify behavior within the upcoming time. When people start taking real efforts to change a behavior, they would be in the fourth stage, the “action” stage. The final stage, “maintenance,” indicates sustainability in doing a behavior for a specific time, which is usually six months at least (Greene, Rossi, Rossi, & Velicer, 1999; Prochaska & DiClemente, 1994).

Method

Design

Using a cross-sectional correlational design, data were collected from the eligible Muslim community-dwelling adults through both face to face and an online survey. An online survey was available for all eligible participants, including those who were associated with but not located at the recruitment sites.

Sample/Participants

The targeted population was Muslims living in the United States. The accessible population was Muslims who could be recruited through Southeastern state contacts. Sampling procedures employed were convenience and snowball sampling. In addition to mosques and community organizations, student associations at a state university and a community clinic were approached to recruit a heterogeneous sample of Muslim adults.
Inclusion criteria were: (1) self-identified as Muslim, (2) adults aged 18 years or older, and (3) able to read, write, and comprehend English. Participants were 148 Muslim adults, with 39 completing the survey in person and 109 completing the survey online. Power analysis indicated a sample size of 122 was needed to conduct multiple regression model providing a statistical power of ≥ 80%, assuming a type I error rate of 0.05, an effect size of Cohen’s $f^2 = 0.15$, and 5% missing data (G*Power version 3.1.9.3).

Measures

A structured self-reported questionnaire was used to obtain the data. The questionnaire consisted of questions about demographic characteristics in addition to items that operationally assessed ACP engagement as well as the health status, ACP awareness, and experiences with decision-making and end-of-life medical treatments.

Health Status and Past Experiences

Health status was assessed with a single-item global self-rated health, which rates health as poor, fair, good, very good, or excellent (CDC, n.d., Idler & Benyamini, 1997). Past EOL treatment experience was assessed by six dichotomous yes-no questions (Amjad et al., 2014). Sample questions are: (1) “have you had a serious illness before,” and (2) “do you know anyone who declares to others (family, friends, healthcare provider) his preferences before he died.”

ACP Engagement

The four-item version of the Advance Care Planning Engagement Survey (ACPES-4) was used to measure ACP engagement (Sudore, Heyland, Barnes, et al., 2017). The overall average score of ACPES-4 could range from 1-5, with five indicating
a higher engagement in ACP. An additional question asking about the time of engagement was added for those who would choose “5 = I have already done it” to assess the stage of change of ACP engagement behavior (action vs. maintenance) (Sudore, Heyland, Barnes, et al., 2017). The tool’s developers estimated Cronbach’s alpha coefficient at 0.86 (Sudore, Heyland, Barnes, et al., 2017). In addition to the total score, according to ACPES-4 responses for each ACP activity, participants were classified into five groups of behavior change: precontemplation (scores 1 and 2), contemplation (score 3), preparation (score 4), action (score 5 and action was done within six months), and maintenance (score 5 and action was done six months ago or more).

Procedure

The principal investigator (PI) in addition to the community insiders at the recruitment sites recruited participants directly through announcing the study and distributing the study flyer that contained a mobile phone scannable QR-code and the survey link to facilitate access to the online survey. The recruitment sites were encouraged to share the electronic version of the flyer with the community members through their own communication platforms, including social media. The study questionnaire was provided through printed copies or online using Qualtrics software. People who were recruited in-person were provided the opportunity to have a printed copy of the questionnaire as well as a stamped envelope to be mailed back after completion. The questionnaire was piloted with five people, and the time to complete the printed version was 20-25 minutes; the time to complete the on-line version was 15-25. Printed copies were returned within four weeks.
Human Subjects Protection

Prior to data collection, study approval was obtained from the institutional review board (IRB) of the University of North Carolina at Greensboro (UNCG). The information sheet at the beginning of the survey included the PI contact information and explained the study timing, risks and strategies to minimize breaches of confidentiality. All measures that protect data confidentiality were maintained. An incentive of $10 electronic gift card was offered voluntarily as a “thank you” for participation.

Statistical Analysis

The sample description and research question one was completed using frequency and percentage, central tendency measures (mean), and variability index (standard deviation) to summarize sociodemographic characteristics, health status, decision making and EOL experiences, and self-reported engagement in any of the four ACP activities, as well as stages of change for ACP engagement. For the second research question, Mann-Whitney U tests were conducted to examine the differences in engagement in ACP activities according to age, gender, ACP awareness, current and past health status, decision-making and EOL treatment experience. All analyses were performed using SPSS v26 (IBM Corp., Armonk, NY). A two-sided p-value < 0.05 was considered statistically significant.

Results

Sociodemographic Characteristics

The sample was comprised of 148 Muslim adults, with the majority of participants living in North Carolina (70.3%). Other persons resided in California
(n =10), Texas (n=8), Virginia (n=3), Michigan (n=8), Florida (n=6), Georgia (n=2), and other states (n=4). Ages ranged from 18 to 79 years old, with a mean age of 36.7 years (SD =13.14). Approximately two-thirds of the sample (65.5%) reported being married (see Table 1).

Table 1

Sample Description (N=148)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
<th>M ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>85 (57.4)</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>62 (41.9)</td>
<td></td>
</tr>
<tr>
<td>Living in NC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>104 (70.3)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>44 (29.7)</td>
<td></td>
</tr>
<tr>
<td>Born in the United States</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>56 (37.8)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>92 (62.2)</td>
<td></td>
</tr>
<tr>
<td>Country of origin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>33 (22.3)</td>
<td></td>
</tr>
<tr>
<td>Africa</td>
<td>11 (7.43)</td>
<td></td>
</tr>
<tr>
<td>Arab countries</td>
<td>71 (47.97)</td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>16 (10.81)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13 (8.78)</td>
<td></td>
</tr>
<tr>
<td>Native language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>30 (20.2)</td>
<td></td>
</tr>
<tr>
<td>Arabic</td>
<td>68 (45.3)</td>
<td></td>
</tr>
<tr>
<td>Urdu</td>
<td>16 (10.8)</td>
<td></td>
</tr>
<tr>
<td>Hausa (Africa)</td>
<td>5 (3.4)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>19 (12.8)</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>97 (65.5)</td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>51 (34.5)</td>
<td></td>
</tr>
</tbody>
</table>
Table 1

Cont.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
<th>M ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>34 (23.0)</td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>18 (12.2)</td>
<td></td>
</tr>
<tr>
<td>Middle Eastern or North African</td>
<td>54 (36.5)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>34 (23.0)</td>
<td></td>
</tr>
<tr>
<td>Other race/ethnicity</td>
<td>8 (5.4)</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>94 (63.5)</td>
<td></td>
</tr>
<tr>
<td>Not employed</td>
<td>54 (36.5)</td>
<td></td>
</tr>
<tr>
<td>Household incomec</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>16 (10.8)</td>
<td></td>
</tr>
<tr>
<td>$20,000 to $34,999</td>
<td>22 (14.9)</td>
<td></td>
</tr>
<tr>
<td>$35,000 to $49,999</td>
<td>38 (25.7)</td>
<td></td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>38 (25.7)</td>
<td></td>
</tr>
<tr>
<td>$75,000 and over</td>
<td>28 (18.9)</td>
<td></td>
</tr>
<tr>
<td>Health status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>2 (1.4)</td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>25 (16.9)</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>53 (35.8)</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>47 (31.8)</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>21 (14.2)</td>
<td></td>
</tr>
<tr>
<td>Hearing about ACP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>78 (52.7)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>69 (46.6)</td>
<td></td>
</tr>
<tr>
<td>Potential decision-maker substitutee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>22 (14.9)</td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>17 (11.5)</td>
<td></td>
</tr>
<tr>
<td>Brother</td>
<td>8 (5.4)</td>
<td></td>
</tr>
<tr>
<td>Sister</td>
<td>7 (4.7)</td>
<td></td>
</tr>
<tr>
<td>Siblings</td>
<td>7 (4.7)</td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>25 (16.9)</td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>37 (25.0)</td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>12 (8.1)</td>
<td></td>
</tr>
<tr>
<td>Imam (Muslim clergy)</td>
<td>3 (2.0)</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>2 (1.4)</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>3 (2.0)</td>
<td></td>
</tr>
</tbody>
</table>
The majority (62.2%) of participants were immigrants with an average length of
time living in the United States of 16 years ($SD = 1.04$). Most of the participants reported
their country of origin as Middle Eastern ($n=56$), Asian ($n=33$), or African ($n=20$)
countries. The other participants reported their countries of origin as the United States
($n=16$), European countries ($n=7$), or other countries ($n=14$). The sample included
diverse racial groups with the majority (77%) self-identified from three racial minority
groups (Asian, Black, and Middle Eastern or North African). The most common self-
reported employment status was either full- or part-time (63.5%). Approximately two-
thirds of the sample reported having at least $35,000$ of household income. About one-
fifth of the total number of participants (18.3%) reported having a poor or fair health
status.

**Advance Care Planning Awareness**

Participants’ awareness of ACP was assessed by one question, “have you ever
heard about advance care planning.” All participants responded to the question. Almost
one-half (46.6%) of the participants had never heard about ACP.
Decision-Making and EOL Experiences

Two thirds of the sample (65%) reported having at least one previous experience with EOL. Less than one third reported experiencing a serious illness, a major surgery in the past, or making a medical decision (26.4%, 32.4%, and 27%, respectively). More than one half (54.7%) of the participants reported having at least one experience related to other people’s EOL medical treatments or decision making. The most common reported EOL care-related experiences were knowing a person who had a bad death because of receiving aggressive or minimal medical treatments were, with 37.8% of the participants reporting at least one EOL experience.

ACP Engagement

Participants’ responses of ACPES-4 items and average scores for each individual ACP activity are presented in Table 2. The average ACPES-4 scores for ACP activities ranged from 1.97 (SD =1.22) for executing official documents reporting EOL medical treatment preferences to 2.09 (SD =1.34) for executing official documents designating a decision-making substitute (health care proxy). Nineteen participants (13%) reported engagement in at least one ACP activity, with five of them (3.4%) reporting engagement in all ACP activities, including executing ACP official documents and conducting ACP discussions. About one-seventh (14.9%) of participants had singed ACP official papers, with 8.8% having a designated health care proxy, and 6.1% having documented their EOL medical preferences and wishes. Less than one-sixth of participants (14.2%) had discussed EOL medical preferences with someone: 7.4% with a decision-maker, and 6.8 % with a healthcare provider. The majority of participants (about two thirds) were in
precontemplation stage of change, reporting no readiness to engage in any ACP activities. Although 17 people were considering either signing official documents, discussing their preferences with a decision-maker substitute, or discussing their preferences with a doctor in the near future, only ten of the 148 participants were considering signing papers designating a decision-maker substitute in the near future.

Table 2
Proportion of Participants at Each Stage of Change for All ACP Activities

<table>
<thead>
<tr>
<th>ACP Activity</th>
<th>M ± SD</th>
<th>PC (n (%)</th>
<th>C (n (%)</th>
<th>PR (n (%)</th>
<th>A (n (%))</th>
<th>M (n (%))</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ready to sign official papers naming a person or group of people to make medical decisionsa</td>
<td>2.12 ± 1.36</td>
<td>105 (70.9)</td>
<td>10 (6.8)</td>
<td>19 (12.8)</td>
<td>5 (3.4)</td>
<td>8 (5.4)</td>
</tr>
<tr>
<td>2. Ready to talk to decision maker about the kind of medical care preferred when becoming very sick or near the EOLb</td>
<td>2.06 ± 1.30</td>
<td>103 (69.6)</td>
<td>17 (11.5)</td>
<td>15 (10.1)</td>
<td>7 (4.7)</td>
<td>4 (2.7)</td>
</tr>
<tr>
<td>3. Ready to talk to a doctor about the kind of medical care preferred when becoming very sick or near the EOLb</td>
<td>2.03 ± 1.27</td>
<td>105 (70.9)</td>
<td>17 (11.5)</td>
<td>14 (9.5)</td>
<td>4 (2.7)</td>
<td>6 (4.1)</td>
</tr>
<tr>
<td>4. Ready to sign official papers putting wishes about the kind of medical care preferred when becoming very sick or near the EOLb</td>
<td>1.99 ± 1.24</td>
<td>107 (72.2)</td>
<td>17 (11.5)</td>
<td>13 (8.8)</td>
<td>5 (3.4)</td>
<td>4 (2.7)</td>
</tr>
</tbody>
</table>

Note. ACP = advance care planning. EOL = end of life. PC = precontemplation stage of change. C = contemplation stage of change. PR = preparation stage of change. A = action stage of change. M = maintenance stage of change. a = data missing for one participant. b = data missing for two participants.

The distribution of participants on stages of change for all ACP activities is presented in Table 3. Overall, the trend of the participants’ distribution on the five stages of change skewed, with the highest number of participants, about two-thirds in precontemplation stage, which is the earliest stage of change of ACP engagement. For
instance, while 72.2% of participants were in precontemplation stage for signing ACP official documents, 6.1% were in the latest stages of change, action and maintenance stages. Participants in the contemplation stage were distributed equally on three ACP activities: conducting informal discussions about EOL care preferences, conducting formal discussions about EOL care preferences, and signing official papers putting wishes about the kind of medical care preferred in future.

Research question two results are provided in Table 3, which shows the Mann-Whitney U test results of engagement in ACP activities scores according to gender, age, ACP awareness, current and past health status, decision-making and EOL experiences. Overall, no significant differences were found between participants regarding engagement in any given ACP activity according to gender and age. However, there were significant differences between groups of people reported having ACP awareness, experience of illness, surgery, decision-making, or EOL treatment compared to other groups who denied having these kinds of experiences. Those who had poor/fair health, had a major surgery, had a serious illness, heard about ACP, made a decision before, knew a deceased person who received aggressive or minimal treatments, or knew a person’s declared EOL preferences had a significantly higher distribution of engagement in all ACP activities compared to their counterparts.
### Table 3
ACP Engagement Score Differences among Participants (N=148)

<table>
<thead>
<tr>
<th>ACP Activity Characteristics</th>
<th>Decision-making substitute</th>
<th>Informal EOL discussions</th>
<th>Formal EOL discussions</th>
<th>EOL preferences determination</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>M</td>
<td>p-value</td>
<td>U</td>
</tr>
<tr>
<td>Gender*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
<td>1</td>
<td>0.522</td>
<td>2755</td>
</tr>
<tr>
<td>Male</td>
<td>84</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age*</td>
<td></td>
<td></td>
<td>0.071</td>
<td>301</td>
</tr>
<tr>
<td>&lt; 60 years</td>
<td>139</td>
<td>72*</td>
<td>0.001</td>
<td>1326</td>
</tr>
<tr>
<td>≥ 60 years</td>
<td>7</td>
<td>100*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heard about ACP</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td>927</td>
</tr>
<tr>
<td>Yes</td>
<td>77</td>
<td>2.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>69</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health status</td>
<td></td>
<td></td>
<td>0.013</td>
<td>1560</td>
</tr>
<tr>
<td>Poor/ Fair</td>
<td>27</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good - Excellent</td>
<td>120</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a serious illness</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td>1486</td>
</tr>
<tr>
<td>Yes</td>
<td>39</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>107</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a major surgery</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td>1002</td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>99</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a decision-making experience</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td>1002</td>
</tr>
<tr>
<td>Yes</td>
<td>39</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>108</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Know a deceased one received ATs</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td>1506</td>
</tr>
<tr>
<td>Yes</td>
<td>55</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>92</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3

Cont.

<table>
<thead>
<tr>
<th>ACP Activity Characteristics</th>
<th>Decision-making substitute</th>
<th>Informal EOL discussions</th>
<th>Formal EOL discussions</th>
<th>EOL preferences determination</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>M</td>
<td>p-value</td>
<td>U</td>
</tr>
<tr>
<td>Know a deceased one received MTs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>55</td>
<td>2</td>
<td>0.009</td>
<td>1916</td>
</tr>
<tr>
<td>No</td>
<td>92</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Know a person declared preferences</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td>1236</td>
</tr>
<tr>
<td>Yes</td>
<td>46</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>101</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * = rank values. ACP = advance care planning. EOL = end of life. ATs aggressive treatments. MTs minimal treatments. a = data missing for three participants. b = data missing for two participants. M = median. U = Mann-Whitney U test.
Discussion

The current cross-sectional descriptive study explored ACP engagement activities among Muslims living in the United States. Moreover, this study examined whether ACP engagement differences existed in any ACP activity according to gender, age, health status, and experiences with end-of-life medical treatments and decision-making that are associated with engagement.

The findings were that Muslims’ engagement in any of ACP activities was relatively lower than that of any other minority population in the United States. These activities included executing official ACP documents and conducting both formal and informal ACP discussions. Further, the prevalence of engagement in any of ACP activities revealed in this study is substantially lower than that was estimated in studies that included only young people. One exception was the rate of formal ACP discussions. While the prevalence of engagement in formal ACP discussions was estimated at 7.4% in this study, it was reported at 2% in previous studies (Kavalieratos et al., 2015; Schnur & Radhakrishnan, 2019). However, the prevalence of engagement in informal ACP discussions in this current study was substantially lower than that prevalence reported in previous studies that included young adults (Kavalieratos et al. 2015; Schnur & Radhakrishnan, 2019; Tripken & Elrod, 2018).

Finding of this study demonstrated that the majority of the participants were in the earliest stage of change of ACP engagement (precontemplation stage), with the lowest proportion of participants in the latest stages of ACP engagement (action or maintenance stages); this indicates a substantial low rate of ACP engagement when compared to the
U.S. national prevalence of ACP engagement, which has been estimated at 36.7% (Yadav et al., 2017). Similarly, the prevalence of ACP engagement among the Muslim population found in this study is lower than what has been estimated in other studies that included racial and faith minority populations, including Muslims (Ko & Berkman, 2012; Ko & Lee, 2014; Rahemi et al., 2019; Rao et al., 2014). For example, about one-half (46%) of a sample of 135 Iranian Americans, where 86% of participants were Muslims aged at least 50 years, reported that they either completed an ACP document or had a discussion about EOL preferences (Rahemi et al., 2019). Ko and Lee (2014) found that one-fifth of a sample of racially diverse older adults (Whites, African Americans, and Hispanics) reported having an ACP official document (Ko & Lee, 2014).

Although exploring the reasons behind the low engagement in ACP was out of this study scope, probable explanations might be suggested. One possible explanation is that the majority of Muslims in the United States are immigrants who came from countries that have no ACP services. It was reported in studies conducted in some Islamic countries that ACP documents were minimally provided there (Al-Jahdali et al., 2012; Silbermann et al., 2015; Zafar et al., 2016). Environmental and social barriers such as health literacy, lack of English proficiency (17% of the Muslim Americans are non-English speakers), system distrust, healthcare access, or other perceived barriers might lead to limited engagement in ACP. Additionally, the current ACP policies advocate for ACP access for only Medicare and Medicaid beneficiaries; however, they have never considered ACP access for Americans who have no health care insurance or for those who have healthcare insurance plans that do not cover ACP conversations.
The substantial low prevalence of ACP engagement among the study sample might indicate that the study participants were unaware about the Islamic teachings regarding the ACP. Islamic law teaches Muslims that conversations about death are not taboo and are mostly encouraged (Sheikh, 1998). In the Qur’an (the Muslims’ holy book), Allah (God) says, “Every soul shall have a taste of death: In the end to us shall you be brought back” (Qur’an 29:57). Despite that Islam teaches Muslims to recall and predict death at any time (Sarhill et al., 2001), it stresses that one’s life is sacred trust from Allah (God) and must be saved (Sheikh, 1998). Furthermore, Islamic teachings seem to be consistent with the self-determination principle of the ACP (Al-Jahdali et al., 2013; Islamic Medical Association of North America [IMANA], 2005). A story that happened in the era of the Prophet Mohammad indicates the importance of considering ACP for the end of life. The Prophet (PBUH) “asked not to be given medications during his illness in view of the fact that his death was imminent and that the treatment was futile. In one of the episodes when he became temporarily unconscious in his final illness the companions, out of love for the Prophet, tried to force feed the medicines. When the Prophet regained consciousness, he was not happy about this and reprimanded the persons responsible for this act” (Al-Jahdali et al., 2013, p. 167). Based on the Prophet Mohammad’s (PBUH) reaction against giving him a medicine at the end of his life without his permission, Muslim scholars concluded two main things related to ACP: (1) when death is imminent, people have the right to self-determination and refusing treatments, and (2) coercion to have a particular treatment is prohibited and coercing people are accountable for such actions (Al-Jahdali et al., 2013). The Islamic Medical
Association of North America (IMANA) has recommended that all Muslims should have a “living will,” an “advance directive,” and a “case manager” to help health care providers to know their wishes when a person is unable to give directions (IMANA Ethics Committee, 2005, p. 37).

No ACP engagement differences between age groups were noticed in this study. This finding contradicts previous ACP research, which found that the likelihood of engagement in ACP activities increased with older adulthood (Carr, 2012; Dobbs et al., 2015, Jang et al., 2017; Moorman & Inoue, 2013; Musa et al., 2015; Teixeira et al., 2015). For example, of a representative national sample of 7,946 American adults, 51.2% of adults older than 65 years had executed an advance directive (AD) compared with only 11.8% of those ages younger than 34 years of age (Rao et al., 2014). Similar findings were reported by another recent national study, which reported a significantly higher ACP engagement among older adults, aged > 65 years, compared to younger ones (39% and 21%, respectively) (McAfee et al., 2019). On the other hand, absence of ACP engagement differences between age groups is consistent with the study by Rahemi et al. (2019), which demonstrated no association between age and engagement in ACP among Iranian Americans, including Muslims. Unlike the majority of studies in ACP literature, which involved older adults, this study included a low number of adults older than 60 years, which could be the reason there was no significant difference in ACP engagement between age groups.

Consistent with other ACP research, this study found no gender difference in engagement in any of ACP activity (Carr, 2012; Ramsey, 2013; Rahemi et al., 2019;
Schnur & Radhakrishnan, 2019). However, this finding conflicts with previous research that found a greater ACP engagement among women than men (Choi et al., 2018; Rao et al., 2014). Absence of either gender or age differences in engagement in different ACP activities could be explained by that regardless of gender and age, most of the Muslim community are not interested in ACP at all. Another potential explanation is regarding Muslims’ typical method of making-decisions. Unlike the American norm of individualism and self-determination, Muslims usually define themselves as a relative part of their families (Hammoud, et al., 2005; Moazam, 2000). Family-centered decision-making style is followed by Muslims worldwide (Beaty, 2015; Da Costa et al., 2000). Further, Muslims may ask for advice from imams (Muslim religious scholars) at the time of decision-making (Padela et al., 2011). Thus, regardless of gender and age, the whole family, including the first-degree relatives and grandparents, may participate actively in the decision-making process (Beaty, 2015; Da Costa et al., 2002; Moazam, 2000; Al-Shahri, 2002). However, there is limited evidence about how decisions are made at the Muslim American family-level and how this might influence engagement in ACP.

Findings indicated that people who reported a poor or fair health condition had more engagement in all ACP activities than their counterparts, which is consistent with other ACP research (Carr, 2012; Moorman & Inoue, 2013; Musa et al., 2015). In addition to the self-reported health status, having had decision-making and EOL experiences was associated with higher level of engagement in all ACP activities. In a previous study of Muslims in the United States, having experienced the loss of a loved one was one factor associated with engagement in EOL planning (Rahemi et al., 2019). Being diagnosed or
having a family loved one who was diagnosed with a life-limiting disease or with a life-threatening illness has also been shown to be associated with an increased the likelihood of engagement in ACP (McAfee et al., 2019). Consistently, having a life-limiting illness was a motivator for considering engagement in ACP (Ward Research, Inc. 2017).

**Limitations**

The study has the following limitations: (1) this study included a relatively low number of older adults (older than 60 years), which might have skewed the ACP engagement results; (2) because the U.S. Muslim population might include immigrants or persons who remain in close communities, the findings might not be reflective of persons who do not read, speak or understand English; (3) because we used convenience and snowball samplings methods, the findings might not represent the views of all Muslim populations living in the United States, persons who chose to participate may have been more open to ACP than those who chose not to participate or vice versa; (4) using self-administered questionnaire puts data validity at risk; (5) using instruments that have not been used previously or validated in Muslims living in the United States could affect the data validity; and (6) collectively, limited English proficiency (according to Pew Research Center (2009), 17% of Muslim Americans have limited English proficiency), possibility of no internet services and electronic devices, as well as intense attention paid to Muslims after domestic and global terrorist attacks might have increased older Muslims’ reluctance to participate in both paper and online surveys. However, to which degree these barriers affected Muslims’ participation in the survey, or in ACP behaviors is out the scope of the current study.
Implications

Although the number of Muslims is increasing in the United States, particularly older adults, a challenge is to engage this population in a range of ACP behaviors that meets cultural and health needs. In practice, healthcare providers should support ACP discussions with Muslim patients and families. Health professional teachers, educators, and institutions should provide trainees with educational materials that focus on Muslim culture. Future research should explore potential reasons behind the low prevalence of engagement among the Muslim population. Future research should include multilanguage surveys, rather than English alone, and include larger numbers of older adults and residents of states other than NC. Future ACP interventions need to be culturally and religiously tailored to the Muslim community living in the United States, which may require communities, providers, and agencies to engage in diversity in a comprehensive manner. Efforts to enact health policies to support practicing ACP in minority populations should be supported.

Conclusion

Muslims’ engagement in ACP activities was relatively low. Advanced care planning awareness and experiences of a serious illness, a past surgery, previous EOL decision-making, or experience with EOL treatment differentiated Muslims who engaged in ACP, with persons who had these kinds of experiences being more likely to engage in ACP. All ACP activities, including executing ACP documents and conducting ACP discussions were presented, however, additional efforts are required to promote ACP engagement among Muslims in the United States. Specific to the stages of change, many
Muslims in the sample were knowledgeable but not ready to engage in any of ACP activities.
CHAPTER V
PREDICTORS OF ADVANCE CARE PLANNING ENGAGEMENT AMONG MUSLIM COMMUNITY-DWELLING ADULTS LIVING IN THE UNITED STATES OF AMERICA: A SOCIAL ECOLOGICAL PERSPECTIVE

Abstract

Background: Advance care planning (ACP) enables people to discuss their needs and concerns, including physical, psychological, social, and spiritual needs before nearing death. Disparities in ACP engagement existed among minority populations. Emerging evidence has supported that engagement in ACP is a multifactorial behavior. The majority of studies that examined determinants of ACP engagement were limited in terms of the absence of theoretical frameworks, and focusing on race variation, older adult population, using untested research tools, and demonstrating inconsistent findings. Minority faith communities, including Muslims living in the United States, have been minimally studied for ACP engagement determinants. Purpose: The purpose of this cross-sectional correlational study was to examine ACP engagement determinants among Muslims living in the United States. Methods: The examined ACP contributing factors were conceptualized into intrapersonal, interpersonal, and community factors using Social-ecological Model. A Self-administered questionnaire measures ACP engagement, and its potential determinants were administered. Convenience and snowball sampling methods were used to recruit participants from Islamic organizations. Multiple linear regression was used to predict ACP engagement. Results: 148 Muslim adults aged 18 to
79 years participated in the study. Among all tested factors, being an Asian American, knowing a deceased one received aggressive or minimal medical treatments near death, born in the United States, had knowledge and awareness about ACP, and accepted of American culture were ACP engagement determinants. **Conclusion:** Future ACP interventions targeted Muslim Americans should take the multifactorial nature of ACP engagement into consideration.

**Keywords:** advance care planning, end of life, decision-making, Muslims, Islam, minority, social-ecological.

**Introduction**

The healthcare system of the United States has experienced a transformational change in models of making decisions related to health. The past dominant paternalistic approach that gives the exclusive authority to the medical team to make decisions on behalf of patients has transformed into a shared decision-making model (Kilbride & Joffe, 2018). Through self-determination, the latter model involves a partnership between patients and their healthcare providers to make decisions that are congruent with their values and preferences (Igel & Lerner, 2016). Shared decision-making is essential when it comes to making difficult decisions, such as those that occur in serious illness or near the end of life (EOL), when many people are not capable of actively engaging in decision-making. The result is often that family members are faced with making emotionally difficult decisions without knowing their loved one’s wishes. Given this challenge, in addition to the fact that the time of an individual’s death is difficult to be
determined accurately, some organizations who advocate for terminally ill patients have initiated efforts for supporting advance care planning (ACP) (IOM, 2015).

Advanced care planning enables people to discuss the holistic potential needs and concerns, including physical, psychological, social, and spiritual, before they become unable to communicate (Austin et al., 2015; Rietjens et al., 2017). Although ACP engagement among American adults has been estimated at 36.7%, a lower rate of engagement has been commonly reported among racial and ethnic minorities, people with less education, people with lower socioeconomic status, younger people, rural residents, and non-English speakers (Barwise et al., 2016; Harrison et al., 2016; McAfee et al., 2017; Rao et al., 2014; Smith, 2008; Sudore et al., 2018; Yadav et al., 2017). Disparities in ACP engagement have led to a substantial decline in the quality of EOL across all populations (IOM, 2015).

Although determinants of disparities in ACP engagement have been the subject of intense debate within the scientific community, it has been agreed that engagement in ACP is a multifactorial phenomenon (IOM, 2015). Uncovering contextual factors that contribute to participation in health-related behaviors has been identified as a crucial element for providing health promotion programs (Simons-Morton et al., 2012). Therefore, understanding the contextual factors that determine people’s engagement in ACP behavior is vital to identify culturally appropriate patient-centered healthcare programs that would promote participation in such behavior (Choi et al., 2018; Ko & Lee, 2014).
Muslims in the United States form a minority population whose engagement in ACP and its contributing factors are little known. It has been projected that Muslims in the United States who are aged 60 years or older will triple to 570,000 by 2030, indicating a growing need for ACP services in this population (Pew Research Center, 2015). The purpose of this study was to examine predictors of ACP engagement among Muslim community-dwelling adults living in the United States. Understanding factors that contribute to ACP engagement might provide a foundation for practical ways to promote participation in ACP and to ensure that the receipt of high quality EOL care is consistent with values and preferences. This study intended to answer the following research questions: (1) What intrapersonal factors are associated with the ACP engagement among Muslim community-dwelling adults living in the United States? (2) What interpersonal factors are associated with the ACP engagement among Muslim community-dwelling adults living in the United States? (3) What community factors are related to the ACP engagement among Muslim community-dwelling adults living in the United States? (4) What combination of intrapersonal, interpersonal, and community factors are associated with ACP engagement among Muslim community-dwelling adults living in the United States?

**Theoretical Framework (Social Ecological Model)**

The current study utilized the Social Ecological Model (SEM) of McLeroy and colleagues (1988) as a conceptual framework to explain the contributing factors of ACP engagement (McLeroy et al., 1988). Many ACP researchers have concluded that disparities in ACP among racial groups could be explained by the integrative effect of
contextual and cultural variables (Choi et al., 2018; Ko & Lee, 2014; McAfee et al., 2019). Through the lens of SEM, this study proposed that ACP engagement is a multifactorial behavior and can be explained by multiple levels of influence. Three SEM constructs were used to conceptualize contributing factors of ACP engagement: intrapersonal factors, interpersonal factors, and community factors. Sociodemographic characteristics, health status, EOL experiences, awareness, knowledge, and attitudes were conceptualized as intrapersonal factors, social support, and acculturation were conceptualized as interpersonal factors. Community factors included community norms and decision-making style.

Method

Design

A cross-sectional correlational design was used. Eligible participants were recruited from several Islamic institutions located in a Southeastern state in the United States. The study questionnaire could be accessed through printed or online method for all eligible participants.

Sample

Sampling procedures used were convenience and snowball sampling. Participants were eligible to participate if they self-identified as Muslims, were eighteen years old or older, lived for at least one year in the United States and were able to read, write, and comprehend English. Power analysis indicated a sample size of 122 participants needed to conduct a multiple regression model providing a statistical power of ≥ 80%, assuming
a type I error rate of 0.05, an effect size of Cohen’s $f^2 = 0.15$, and 5% missing data (G*Power version 3.1.9.3).

Measures

The current study used a structured self-reported questionnaire. The questionnaire consisted of items that operationally assessed ACP engagement as well as intrapersonal, interpersonal, and community factors.

Intrapersonal Factors

Interpersonal factors included sociodemographic characteristics, health status, experiences of decision-making and EOL medical treatments, awareness about ACP, ACP knowledge, and attitudes toward ACP. A set of questions was used to assess selected sociodemographic characteristics, including age, gender, race, marital status, place of birth, native language, country of origin, length of time living in the United States, employment, income, and religiosity. Health status was assessed using a single-item global self-rated health, which rates health as poor, fair, good, very good, or excellent (CDC, n.d., Idler & Benyamini, 1997). Awareness of ACP was measured by one question, “have you ever heard about ACP?” Experiences of decision-making and EOL medical treatments were assessed by six dichotomous yes-no questions (Amjad et al. 2014). Knowledge about ACP was assessed by using a six-item subscale adapted from Advance Care Planning Engagement Survey (ACPES) (Sudore et al., 2013). The average total score could range from the 1 to 5, with five represents the highest value of ACP knowledge. The primary developers estimated Cronbach's alpha coefficient of the knowledge subscale at 0.84 (Sudore et al., 2013). However, a higher value of Cronbach’s
alpha coefficient was calculated in this study, with $\alpha = 0.95$. Attitudes toward ACP were measured by a 12-item tool developed by Fried et al. (2012). The tool is divided into two equal sets of items, with one 6-item set measures pros of ACP and another 6-item set that measure cons of ACP. The average total score could range from 1 to 5, with a higher average score indicating greater pros or cons of ACP. Internal reliability testing was performed in a group of 304 older adults, with an estimated value of Cronbach’s alpha coefficient as 0.86 for pros and cons subscales (Fried et al., 2012). Close values of Cronbach’s alpha coefficient were calculated in the current study, with $\alpha = 0.88$ for pros subscale and $\alpha = 0.85$ for cons subscale.

**Interpersonal Factors**

Interpersonal factors consisted of social support and acculturation. Social Support was measured by the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988). The MSPSS is 12-item tool that measures a person's social support received from family (Items 3, 4, 8, and 11), friends (Items 6, 7, 9, and 12), and significant others (Items 1, 2, 5, and 10) (Zimet et al., 1988). The total score ranges from 12 to 84, with the higher scores indicating greater levels of social support (Dahlem, Zimet & Walker, 1991; Zimet, Powell, Farley, Werkman & Berkoff, 1990). Zimet et al., 1988 reported Cronbach's alpha coefficient as $\alpha = 0.88$, but it was calculated as $\alpha = 0.94$ in this study. The Acculturation Scale for Muslim Americans (ASMA) was used in the current study to assess participants' acculturation (Bagasra & Mackinem, 2019). The tool consists of 13 items divided into two subscales. First, the Adherence to Islamic Identity Subscale (AIIS) consists of 5 items measure Islamic identity, with total
score ranges from 5 to 25. Second, the Conformity to American Norms Subscale (CANS) consists of eight questions and indicates how much a Muslim person is adopting the American culture with total score ranges from 8 to 40 (Bagasra & Mackinem, 2019). Cronbach’s alpha coefficient was calculated as 0.72 for AIIS, and as \( \alpha = 0.79 \) for CANS (Bagasra & Mackinem, 2019). In the current study, Cronbach’s alpha coefficients were calculated as \( \alpha = 0.69 \) for AIIS, and as \( \alpha = 0.82 \) for CANS.

**Community Factors**

Community factors were measured by the community norms and the decision-making style. The community norms were measured by the ACP Values/Belief scale developed by Fried et al. (2012). The average total score could range from 1 to 5, with a higher average score indicating more positive values and beliefs toward ACP. Internal consistency reliability was estimated by Cronbach’s alpha coefficient, with \( \alpha = 0.89 \) (Fried et al., 2012). In this study, Cronbach’s alpha coefficient was estimated as \( \alpha = 0.83 \).

Decision-making style was assessed using the Control Preferences Scale (CPS), which is a one-item tool with five response options (Degner, Sloan et al., 1997). Consistent with the authors’ recommendation, this study clustered participants according to their responses into three categories of role responses: active (autonomous), collaborative, and passive (Degner, Kristjanson et al., 1997).

**Outcome Variable (ACP Engagement)**

The four-item version of the Advance Care Planning Engagement Survey (ACPES-4) was used to measure ACP engagement (Sudore, Heyland, Barnes, et al., 2017). The overall average score of ACPES-4 could range from 1 to 5, with a score of
five indicating the highest engagement in ACP (Sudore, Heyland, Barnes, et al., 2017). The tool’s developers estimated Cronbach’s alpha coefficient at 0.86 (Sudore, Heyland, Barnes, et al., 2017). The alpha for this study report was $\alpha = 0.89$.

**Procedure**

The PI, with help from the community leaders and insiders, recruited people directly at the recruitment sites. Potential eligible people were invited to participate in the study through face to face announcement and distributing the study flyer. The flyer contained a smartphone scannable QR-code and the survey link to access the electronic survey. The PI encouraged community insiders and leaders at the recruitment sites to distribute the electronic version of the flyer to their followers by using their communication channels. The study questionnaire was provided in both printed and electronic (Qualtrics) forms. Those who were recruited in-person had the option of receiving a printed copy of the questionnaire in addition to a stamped envelope. The questionnaire was piloted with five people, and the time to complete the paper form was 20-25 minutes. The time to take the questionnaire online was piloted as 15 to 25 minutes. Paper copies were mailed back within four weeks.

**Human Subjects Protection**

Study approval from the IRB of the University of North Carolina at Greensboro (UNCG) was obtained prior data collection. The PI attached an information sheet to the survey containing the study timing, risks, and strategies to minimize breaching confidentiality along with the PI contact information. All measures that protect data
confidentiality were maintained. An incentive of $10 electronic gift card was offered voluntarily as a “thank you” for participation.

**Statistical Analysis**

The goal of statistical analysis was to explore the associations between the outcome variable, “ACP engagement,” and the potential predictors. Descriptive statistics of frequency and percentage, central tendency measure (mean), and variability index (standard deviation) were used to describe and summarize participants’ responses. For continuous variables, outliers and normality were examined in univariate analysis using boxplots, normal Q-Q plots, and Kolmogorov-Smirnov tests. Advanced care planning engagement, length of time in the United States, attitudes (pros), and attitudes (cons) were transformed by using natural log method because the normality was violated. Dummy coding was performed for sociodemographic characteristics, decision-making and EOL experiences, and decision-making style. Associations between ACP engagement natural Log scores (ACPELSs) and continuous variables were examined by the Pearson product-moment correlation; however, for dichotomous variables, point-biserial correlation was used. Simultaneous multiple linear regression was used to model the outcome, “ACP engagement” with all independent variables. Multiple imputations were used for missed average scores. All analyses were performed using the Statistical Package for Social Sciences (SPSS) version 26 and Mplus software (IBM Corp., Armonk, NY; Muthen & Muthen, 2011). A two-sided p-value < 0.05 was considered statistically significant.
Results

Intrapersonal Factors

The sample was comprised of 148 participants who self-identified as Muslim Adults and were able to read, write, and understand the English language. The mean age was 36.7 years ($SD = 13.14$). The majority (62.2%) of participants were immigrants with an average length of the time living in the United States reported as 16 years ($SD = 1.04$). About two-thirds of the total sample (65.5%) were married. The sample was diverse in racial identity, with 77% self-identified as Asian, Black, Middle Eastern, or North African. The majority (63.5%) were employed. Approximately two-thirds of the total sample reported $35,000$ of household income or more. A majority (81.7%) reported having good or better health status.

Approximately two-thirds (65%) of the total sample had experienced one of the measured decision-making and EOL experiences. Less than one-third had a serious illness, a major surgery, or had made a health-related decision (26.4%, 32.4%, and 27%, respectively). The most commonly reported experiences of decision-making and EOL (37.8%) were: knowing a person who had a bad death because of receiving either aggressive or minimal medical treatments.

The study participants reported a relatively low level of knowledge about ACP, with a mean score of 2.73 ($SD = 1.20$) out of a possible score of 5. Attitudes toward ACP were relatively positive, with the mean of the average scores of ACP pros being higher than that for ACP cons ($3.68 \pm 0.90$ and $2.81 \pm 0.98$, respectively).
Interpersonal Factors

Interpersonal factors were measured by social support and acculturation. Social support among the study participants was relatively high, with an average of 64.93 ($SD = 15.15$). However, the total score of social support varied, ranging from 12 to 84. The study participants reported high adherence to Islamic culture, with an average total score of Adherence to Islamic Identity Subscale (AIIS) of 19.4 ($SD = 3.81$). In contrast, the participants reported a relatively moderate adaptation of the American culture with an average total score of 21.8 ($SD = 7.18$) for Conformity to American Norms Subscale (CANS).

Community Factors

The average total score of the perceived community ACP norms varied among participants with a range from 1 to 5. The study participants exhibited relatively positive values and beliefs regarding ACP with a mean of 3.38 ($SD = 0.81$) for an average of perceived community ACP norms. In respect to the decision-making style, the majority of participants (60.8%) selected an active role as a preferred decision-making style. The remaining participants selected either the shared decision-making style or passive decision-making style (27% and 10.9%, respectively) (see Table 4).

ACP Engagement

Participants’ engagement in ACP activities was measured using the four-item version of the Advance Care Planning Engagement Survey (ACPES-4) (Sudore, Heyland, Barnes, et al., 2017). In the current study, ACPES-4 average scores ranged from 1 to 4.
The participants exhibited a low engagement in ACP, as indicated by a low mean of ACP engagement average scores ($M = 2.03$, $SD = 1.11$).

Table 4

Participants’ Preferred Decision-making Styles ($N=148$)*

<table>
<thead>
<tr>
<th>Response</th>
<th>Decision-making style</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer to make decision about what treatment I will receive.</td>
<td>Active role</td>
<td>37 (25.0)</td>
</tr>
<tr>
<td>I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.</td>
<td>Active role</td>
<td>53 (35.8)</td>
</tr>
<tr>
<td>I prefer that my doctor and I share responsibility for deciding which treatment is best for me.</td>
<td>Collaborative role</td>
<td>40 (27.0)</td>
</tr>
<tr>
<td>I prefer to leave all decisions regarding treatment to my doctor.</td>
<td>Passive role</td>
<td>6 (4.1)</td>
</tr>
<tr>
<td>I prefer that my doctor makes the final decision about which treatment will be use, but seriously considers my opinion.</td>
<td>Passive role</td>
<td>10 (6.8)</td>
</tr>
</tbody>
</table>

*Note. *$a$* data missing for two participants.

Several intrapersonal and interpersonal factors were associated with ACP engagement natural log scores (ACPELSs). Table 5 shows the results of Pearson product-moment and the point-biserial correlations. None of the community factors were associated with ACPELSs. There was a positive significant linear relationship between ACPELSs and several factors, including: The length of time residing in the United States, acculturation scores, ACP knowledge, being married, nonimmigrant status, Asian race, employment, awareness about ACP, or previous decision-making and EOL experiences.
Higher acculturation scores, being Middle Eastern, having an income lower than $50,000, and having better health, were significantly associated with lower ACPELSs.

Table 5

Correlations between ACPE\textsuperscript{a} and Participants’ Intrapersonal, Interpersonal, and Community Factors (N=148)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>\textit{r}</th>
<th>Characteristic</th>
<th>\textit{r}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.001</td>
<td>Had a surgery in the past</td>
<td>0.309**</td>
</tr>
<tr>
<td>Female vs. male</td>
<td>-0.103</td>
<td>Made a health decision</td>
<td>0.523**</td>
</tr>
<tr>
<td>Married vs. otherwise</td>
<td>0.187*</td>
<td>Know a deceased one received ATs</td>
<td>0.415**</td>
</tr>
<tr>
<td>Born in the United States</td>
<td>0.465**</td>
<td>Know a deceased one received MTs</td>
<td>0.228**</td>
</tr>
<tr>
<td>Asian vs. White</td>
<td>0.231**</td>
<td>Know a person declared preferences</td>
<td>0.425**</td>
</tr>
<tr>
<td>Black vs. White</td>
<td>0.005</td>
<td>ACP Knowledge</td>
<td>0.602**</td>
</tr>
<tr>
<td>Middle Eastern vs. White</td>
<td>-0.379**</td>
<td>ACP attitudes (Pros\textsuperscript{a})</td>
<td>0.150</td>
</tr>
<tr>
<td>Other race vs. White</td>
<td>0.039</td>
<td>ACP attitudes (Cons\textsuperscript{a})</td>
<td>0.105</td>
</tr>
<tr>
<td>Employed vs. otherwise</td>
<td>0.363**</td>
<td>Acculturation (CANS)</td>
<td>0.510**</td>
</tr>
<tr>
<td>Income &lt; $50,000 vs. ≥ $50,000</td>
<td>-0.290**</td>
<td>Acculturation (AIIS)</td>
<td>-0.254**</td>
</tr>
<tr>
<td>Years in the United States\textsuperscript{a}</td>
<td>0.319**</td>
<td>Social support</td>
<td>0.132</td>
</tr>
<tr>
<td>Health status</td>
<td>-0.273**</td>
<td>Norms</td>
<td>0.039</td>
</tr>
<tr>
<td>Religiosity</td>
<td>-0.028</td>
<td>Passive role vs. shared role</td>
<td>-0.112</td>
</tr>
<tr>
<td>Heard about ACP vs. otherwise</td>
<td>0.559**</td>
<td>Active role vs. shared role</td>
<td>0.098</td>
</tr>
<tr>
<td>Had a serious illness</td>
<td>0.262**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: \textsuperscript{a} = transformed scores (natural log). * = correlation is significant with \textit{p} < 0.05. ** = correlation is significant with \textit{p} < 0.01. ACPE = advance care planning engagement. ATs = aggressive treatments. MTs = minimal treatments. AIIS = Adherence to Islamic Identity Subscale. CANS = Conformity to American Norms Subscale.

Table 6 provides the results of simultaneous multiple linear regression models utilized to predict ACP engagement natural log scores (ACPELSs) when intrapersonal, interpersonal, and community factors might relate to ACP engagement.
Table 6

Simultaneous Multivariable Linear Regression Analysis of ACPE of Muslims Living in the United States ($N=148$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$n$ (%)</th>
<th>$M \pm SD$</th>
<th>Model 1 (RQ 1)</th>
<th>Model 2 (RQ 2)</th>
<th>Model 3 (RQ 3)</th>
<th>Model 4 (RQ 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support</td>
<td>64.9±15.15</td>
<td>0.002</td>
<td>(-0.005, 0.009)</td>
<td>(-0.008, 0.004)</td>
<td>0.364</td>
<td></td>
</tr>
<tr>
<td>Acculturation/AlIS</td>
<td>19.6±3.81</td>
<td>-0.007</td>
<td>(-0.036, 0.023)</td>
<td>(-0.029, 0.019)</td>
<td>0.593</td>
<td></td>
</tr>
<tr>
<td>Acculturation/CANS</td>
<td>21.8±7.18</td>
<td>0.034</td>
<td>(0.018, 0.050)</td>
<td>0.001</td>
<td>0.017</td>
<td></td>
</tr>
<tr>
<td>Community norms</td>
<td>3.38±0.81</td>
<td>0.008</td>
<td>(-0.127-0.143)</td>
<td>(-0.142, 0.083)</td>
<td>0.498</td>
<td></td>
</tr>
<tr>
<td>Active DMR vs. shared DMR</td>
<td>90 (60.8)</td>
<td>-0.167</td>
<td>(-0.549-0.214)</td>
<td>(-0.360, 0.179)</td>
<td>0.387</td>
<td></td>
</tr>
<tr>
<td>Passive DMR vs. shared DMR</td>
<td>16 (10.8)</td>
<td>0.259</td>
<td>(-0.185-0.314)</td>
<td>(-0.234, 0.095)</td>
<td>0.276</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>62 (41.9)</td>
<td>-0.046</td>
<td>(-0.207, 0.115)</td>
<td>(-0.164, 0.154)</td>
<td>0.935</td>
<td></td>
</tr>
<tr>
<td>Born in the United States</td>
<td>56 (37.8)</td>
<td>0.204</td>
<td>(-0.020, 0.429)</td>
<td>(0.033, 0.463)</td>
<td>0.003</td>
<td></td>
</tr>
</tbody>
</table>
Table 6
Cont.

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
<th>M ± SD</th>
<th>Model 1 (RQ 1)</th>
<th>Model 2 (RQ 2)</th>
<th>Model 3 (RQ 3)</th>
<th>Model 4 (RQ 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married vs. Otherwise RC</td>
<td>97 (65.5)</td>
<td>0.047 (-0.141, 0.236)</td>
<td>0.518</td>
<td>0.046 (-0.143, 0.235)</td>
<td>0.530</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian vs. White RC</td>
<td>34 (23.0)</td>
<td>0.113 (-0.110, 0.337)</td>
<td>0.191 (-0.135, 0.237)</td>
<td>0.329 (-0.038, 0.429)</td>
<td>0.031 (-0.042, 0.195)</td>
<td></td>
</tr>
<tr>
<td>African American vs. White RC</td>
<td>18 (12.2)</td>
<td>-0.135 (-0.249, 0.159)</td>
<td>0.237 (-0.090, 0.317)</td>
<td>-0.329 (-0.010, 0.155)</td>
<td>0.704 (-0.042, 0.031)</td>
<td></td>
</tr>
<tr>
<td>Middle Eastern vs. White RC</td>
<td>54 (36.5)</td>
<td>-0.090 (-0.250, 0.107)</td>
<td>0.312 (-0.083, 0.090)</td>
<td>0.244 (-0.042, 0.155)</td>
<td>0.917 (-0.010, 0.331)</td>
<td></td>
</tr>
<tr>
<td>Other race vs. White RC</td>
<td>08 (5.40)</td>
<td>-0.269 (-0.435, 0.046)</td>
<td>0.544</td>
<td>-0.194 (0.486)</td>
<td>0.269</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed vs. otherwise RC</td>
<td>94 (63.5)</td>
<td>0.050 (-0.134, 0.234)</td>
<td>0.480</td>
<td>0.190 (-0.094, 0.172)</td>
<td>0.897</td>
<td></td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$50,000 vs. ≥$50,000 RC</td>
<td>76 (51.4)</td>
<td>-0.088 (-0.255, 0.079)</td>
<td>0.176</td>
<td>-0.251 (-0.063, 0.094)</td>
<td>0.123</td>
<td></td>
</tr>
<tr>
<td>Health status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.41 ± 0.98</td>
<td></td>
<td>-0.141 (-0.115, 0.033)</td>
<td>0.113</td>
<td>-0.055 (0.363)</td>
<td>-0.030</td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>$n$ (%)</td>
<td>$M \pm SD$</td>
<td>Model 1 (RQ 1)</td>
<td>Model 2 (RQ 2)</td>
<td>Model 3 (RQ 3)</td>
<td>Model 4 (RQ 4)</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------</td>
<td>------------</td>
<td>----------------</td>
<td>----------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Religiosity</td>
<td>7.41 ± 1.59</td>
<td>0.025</td>
<td>(-0.024, 0.074)</td>
<td>0.190</td>
<td>0.036</td>
<td>(-0.012, 0.084)</td>
</tr>
<tr>
<td>Heard about ACP</td>
<td>Yes vs. No&lt;sup&gt;RC&lt;/sup&gt;</td>
<td>78 (52.7)</td>
<td>0.231</td>
<td>(0.037, 0.424)</td>
<td>0.002</td>
<td>0.201</td>
</tr>
<tr>
<td>Had a serious illness</td>
<td>Yes vs. No&lt;sup&gt;RC&lt;/sup&gt;</td>
<td>39 (26.4)</td>
<td>-0.002</td>
<td>(-0.207, 0.203)</td>
<td>0.979</td>
<td>-0.022</td>
</tr>
<tr>
<td>Had a major surgery</td>
<td>Yes vs. No&lt;sup&gt;RC&lt;/sup&gt;</td>
<td>48 (32.4)</td>
<td>0.077</td>
<td>(-0.114, 0.267)</td>
<td>0.299</td>
<td>0.118</td>
</tr>
<tr>
<td>Had a decision-making experience</td>
<td>Yes vs. No&lt;sup&gt;RC&lt;/sup&gt;</td>
<td>40 (27.0)</td>
<td>0.051</td>
<td>(-0.264, 0.366)</td>
<td>0.675</td>
<td>0.005</td>
</tr>
<tr>
<td>Know a deceased one received ATs</td>
<td>Yes vs. No&lt;sup&gt;RC&lt;/sup&gt;</td>
<td>56 (37.8)</td>
<td>0.250</td>
<td>(0.050, 0.450)</td>
<td>0.001</td>
<td>0.234</td>
</tr>
<tr>
<td>Know a deceased one received MTs</td>
<td>Yes vs. No&lt;sup&gt;RC&lt;/sup&gt;</td>
<td>56 (37.8)</td>
<td>-0.149</td>
<td>(-0.340, 0.042)</td>
<td>0.044</td>
<td>-0.164</td>
</tr>
</tbody>
</table>
Table 6

Cont.

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
<th>M ± SD</th>
<th>Model 1 (RQ 1)</th>
<th>Model 2 (RQ 2)</th>
<th>Model 3 (RQ 3)</th>
<th>Model 4 (RQ 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Know a person declared preferences</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes vs. No[^RC]</td>
<td>47 (31.8)</td>
<td>-0.057</td>
<td>(-0.291, -0.177)</td>
<td>-0.060</td>
<td>(-0.283, 0.164)</td>
<td>0.491</td>
</tr>
<tr>
<td>Age in years</td>
<td>35.8 ± 12.95</td>
<td>0.093</td>
<td>(-0.204, 0.389)</td>
<td>0.182</td>
<td>(-0.115, 0.480)</td>
<td>0.115</td>
</tr>
<tr>
<td>Years in the United States</td>
<td>17.03 ± 12.54</td>
<td>0.022</td>
<td>(-0.088, 0.132)</td>
<td>-0.011</td>
<td>(-0.123, 0.102)</td>
<td>0.808</td>
</tr>
<tr>
<td>ACP knowledge</td>
<td>2.73 ± 1.20</td>
<td>0.118</td>
<td>(0.040, 0.196)</td>
<td>0.129</td>
<td>(0.047, 0.210)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>ACP attitudes (pros)</td>
<td>3.68 ± 0.90</td>
<td>0.048</td>
<td>(-0.223, 0.318)</td>
<td>0.021</td>
<td>(-0.296, 0.339)</td>
<td>0.862</td>
</tr>
<tr>
<td>ACP attitudes (cons)</td>
<td>2.81 ± 0.98</td>
<td>0.015</td>
<td>(-0.210, 0.239)</td>
<td>-0.017</td>
<td>(-0.249, 0.216)</td>
<td>0.853</td>
</tr>
<tr>
<td>ACP engagement</td>
<td>2.03 ± 1.11</td>
<td>0.620</td>
<td>0.258</td>
<td>0.021</td>
<td>0.663</td>
<td></td>
</tr>
</tbody>
</table>

Note. RQ = research question. SD = standard deviation. CI = confidence interval. RC = reference category. ACPE = advance care planning engagement. DMR = decision-making role. AIIS = Adherence to Islamic Identity Subscale. CANS = Conformity to American Norms Subscale. ATs = aggressive treatments. MTs = minimal treatments.
Natural log scores of ACP engagement, length of time in the United States, attitudes (pros), and attitudes (cons) were used for this analysis. The percentage of variation in ACPELSs explained by a regression model varied between all multiple linear regression models. Compared to all multiple linear regression models, the fourth model explained the highest variation in ACPELSs mean, with approximately 66.3% of the variation ($R^2 = 0.663$). While the first model explained the second-highest variation in ACPELSs mean ($R^2 = 0.620$), the second and third models explained the lowest variation, 25.8%, and 2.1%, respectively. Overall, the results of this analysis show that among all tested factors, five intrapersonal factors, in addition to one interpersonal factor were related to the ACPELSs. Neither of the community factors was related to the ACPELSs.

The results of the first model revealed that five intrapersonal factors were significantly related to the predicted mean participants' ACPELSs. While the predicted mean decreased for knowing a deceased one who received minimal EOL medical treatments, the predicted mean increased for those who were born in the United States, having an awareness of ACP, knowing a deceased one who received aggressive EOL medical treatments, and knowledge about ACP. The predicted mean ACPELSs was 0.149 points lower for those who had known a deceased one who received minimal EOL medical treatments compared to those who had not known a deceased one who received minimal EOL medical treatments, adjusting for other intrapersonal factors ($b = -0.149$, $p = 0.044$). The predicted mean ACPELSs was 0.204 points greater for those who born in the United States versus those who were born in other countries, adjusting for other
intrapersonal factors ($b = 0.204, p = 0.019$). The predicted mean ACPELSs was 0.231 points greater for those who had heard about ACP compared to those who had not heard about ACP, adjusting for other intrapersonal factors ($b = 0.231, p = 0.002$). The predicted mean ACPELSs was 0.250 points greater for those who knew a deceased one received aggressive EOL medical treatments compared to those who had not known a deceased one who received aggressive EOL medical treatments, adjusting for other intrapersonal factors ($b = 0.250, p = 0.001$). For every additional point increase in the ACP knowledge mean score, the predicted mean of ACPELSs increased by 0.118 points, adjusting for other intrapersonal factors ($b = 0.118, p = 0.048$).

The second model revealed that conformity to American norms acculturation subscale (CANS) mean score was the only interpersonal factor that significantly predicted mean participants’ ACPELSs. For every additional point increase in the CANS mean score, the predicted mean of ACPELSs increased by 0.034 points, adjusting for social support and adherence to Islamic identity subscale ($b = 0.034, p = <0.001$). Unlike the first and second models, the third model showed no factors that had a significant relationship with ACPELSs. As seen in Table 6, no community factor significantly predicted the mean participants’ ACPELSs.

The fourth model was carried out to collectively predict study participants’ intrapersonal, interpersonal, and community characteristics’ associations with the mean ACPELSs. The results of the model indicated that in addition to all intrapersonal and interpersonal ACPELSs predictors found in the previous models, the Asian race became an additional ACPELSs predictor ($p = 0.031$). The predicted mean ACPELSs was 0.195
points greater for those who self-reported as Asian compared to those who self-reported as White, adjusting for other intrapersonal, interpersonal, and community factors.

Discussion

This novel study examined potential intrapersonal, interpersonal, and community factors associated with ACP engagement behavior among Muslim community-dwelling adults living in the United States. Overall, while several intrapersonal and interpersonal factors were associated with ACP engagement, none of the community factors were associated with ACP engagement among our sample of Muslim community-dwelling adults.

Average scores that were reported by our sample indicate low levels of engagement in ACP, low ACP awareness and knowledge, negative attitudes (cons) toward ACP, and low acculturation with the American culture. Although low level of ACP engagement is common among minority populations, Muslim American adults’ engagement in ACP indicated in this study is substantially lower than any minority population living in the United States (Ko & Berkman, 2012; Ko & Lee, 2014; Rao et al., 2014; Yadav et al., 2017). Although knowledge about ACP has been used interchangeably with the awareness of ACP in the current literature; they were measured as two different constructs in this study. Muslim adults in this study reported a deficit in ACP knowledge and awareness, which is consistent with other minority populations (Dobbs et al., 2015; Eckemoff et al. 2018; Gao et al., 2015; Kermel-Schiffman & Werner, 2017; Kwak & Salmon, 2007; Ramsey, 2013; Rao et al., 2014; Teixeira et al., 2015; Wittenberg-Lyles et al., 2008). Both ACP knowledge and awareness were positively
associated with ACP engagement. These findings are similar to those reported in previous ACP research (Jang et al., 2017; Ko & Lee, 2014).

Although pairwise correlation testing revealed significant relationships between ACP engagement and several sociodemographic characteristics, including income, length of time in the United States, marital status, immigration status, race (Asia or Middle East), and employment status, the effect of most of these characteristics on ACP engagement disappeared when their influences were adjusted for by intrapersonal, interpersonal, and community factors. However, the effects of these sociodemographic characteristics remained in those who were Asian or nonimmigrant. The study finding that the minority group of Asians had greater ACP engagement than their White counterparts is similar to what Carr (2012) reported. However, it is inconsistent with other study findings of lower ACP engagement among minority populations compared to Whites (Choi et al., 2018; Orlovic et al., 2019). Although some studies found that race was a factor in the engagement in ACP, those that controlled for the influence of other variables found that race alone is not a determinant factor in the level of engagement in ACP (Choi et al., 2018; Ko & Lee, 2014; McAfee et al., 2019). This finding suggests that additional research is warranted to explore to what extent race can predict engagement in ACP.

Despite adjusting for the effects of all tested variables, being born in the United States remained a determinant of high ACP engagement among Muslim Americans in this study. Those who were born in the United States (non-immigrants) might be more knowledgeable and aware of ACP than those who were not born in the United States
(immigrants). In this line, Eckemoff et al. (2018) found that first-generation Russian American immigrants have lower awareness and knowledge about ACP than their non-immigrants counterparts. Unlike non-immigrant Russians, immigrant Russians confused living wills with the financial last wills and testaments and believed that talking about ACP and death was a taboo topic in Russian culture (Eckemoff et al., 2018).

Health condition and experiencing EOL medical treatments might encourage people to consider planning for their own end of lives (Ward Research, Inc. 2017). In our study, the self-reported health status was negatively associated with ACP engagement, similar to findings observed in previous research (Carr, 2012; Choi et al., 2018; Musa et al., 2015). However, health status was not related to ACP engagement after controlling for other factors. This finding is similar to Moorman and Inoue (2013), who observed no relationship between health status and the completion of ACP documents (Moorman & Inoue, 2013). We found that having the experience of a serious illness predicted ACP engagement, which is consistent with previous studies (Amjad, Towle & Fried, 2014; McAfee et al., 2019). Likewise, we found that having an experience of knowing a deceased person who received aggressive or minimal EOL treatments was an ACP engagement determinant, which is consistent with Amjad et al. (2014) findings.

Reported average scores of attitudes toward ACP and community norms in our study indicated relative positive attitudes and norms toward ACP, which is congruent with attitudes and norms held by Muslim Americans in a previous study (Duffy et al., 2006) as well as in other populations (Ingravallo, 2018; Lee et al., 2016; McAfee et al., 2019). However, our study findings indicated that neither attitudes toward ACP nor
community norms were significantly related to engagement in ACP, which is inconsistent with findings from other studies of American adults (Ko & Lee, 2014; McAfee et al., 2019; Rahemi, 2017). Norms and attitudes toward ACP found in our study might reflect the Islamic law perspective, which appears to be with an agreement with the ACP (Al-Jahdali et al., 2013; Islamic Medical Association of North America, 2005).

In this study, two interpersonal factors were examined for influence on ACP engagement; acculturation and social support. As a central interpersonal factor for immigrants’ lives, acculturation was investigated in this study for its impact on ACP engagement (Hong, Yi, Johnson & Adamek, 2018; Jang et al., 2017). Compared to American culture, Islamic culture was more prominent among the participants, indicating a higher adherence to Islamic traditions. However, greater acculturation with American culture contributed to higher engagement in ACP. Similar to our findings, greater acculturation was associated with a higher likelihood of engagement in ACP among Korean Americans and Latinos (Dobbs et al., 2015; Kelley et al., 2010). Higher acculturation might lead to better knowledge and awareness of ACP that might cause greater engagement in ACP (Dobbs et al., 2015; Gao et al., 2015).

**Implications**

One of the essential implications of this study is that healthcare professionals who provide direct care, educate new professional generations, evaluate the quality of care, and conduct research with the Muslim population should be aware that Muslims in the United States have a lower engagement in ACP and that this lower rate of ACP is correlated with immigrant status, lack of awareness and knowledge about ACP, lack of
experience with EOL situations, and stronger identity with Islamic culture. Health care providers can address this disparity of ACP engagement in Muslim adults by initiating ACP discussions with Muslim patients in a culturally competent manner. To provide culturally competent ACP services, healthcare workers should be aware about Muslim teachings and traditions around ACP and EOL. Further they should know ACP contributing factors when initiating ACP discussions with Muslim population, which should facilitate and improve culturally competent EOL care.

Appropriately tailored interventional programs that address ACP awareness and knowledge should be initiated with consideration of the context of the Muslim population. Future research should provide multi-language surveys. Collaborative efforts are needed with the involvement of the Muslim community and religious leaders, clergy services in hospital settings, nurses and other health care professionals, and social services to discuss innovative methods to mitigate ACP engagement disparity among the Muslim population.

**Limitations**

There were several limitations noted in this study. First, a bias could exist because of using convenience and snowball sampling techniques. Second, although using a cross-sectional corralational design enables examining correlations between variables, it limits the ability to examine causality. Third, using self-administered questionnaires and surveys puts data validity at risk of bias. Fourth, using instruments that have not been used previously or validated in Muslims living in the United States could affect the
validity of the findings. Fifth, the administration of only the English questionnaires precludes participation and knowledge of those who do not read English.

**Conclusion**

In summary, this study is unique in terms of examining ACP engagement behavior based on a broad contextual perspective of influence derived from the SEM conceptual framework (McLeroy et al., 1988). Unlike previous studies that explored ACP engagement among American Muslims (Duffy et al., 2006; Rahemi et al., 2019), this study included a diverse sample of Muslim adults in terms of age, race, country of origin, native languages, and immigrant and health status. Several intrapersonal and interpersonal factors, but none of the community factors were associated with ACP engagement among our sample of Muslim community-dwelling adults.
CHAPTER VI

SUMMARY

Dramatic improvement in health technology, surgical techniques, and new pharmacological treatments can extend life physically. However, increased longevity, terminal illness, and other chronic health conditions require quality of life and patient-centered treatment decisions. Federal policy and public health advocacy agencies have encouraged advance care planning (ACP) as a strategy to assure people’s right to self-determination. Engagement in ACP has been increasingly considered as a health behavior that benefits individuals and the entire community in terms of facilitating decision-making when an individual becomes incapable of making decisions on their own. The estimated rate of Americans’ engagement in ACP is lower than the national target/objective. However, disparities within the American population regarding ACP engagement are prevalent among minority groups. To improve ACP engagement among American adults, understanding ACP engagement behavior among minorities is crucial. This chapter summarizes the information discussed in the previous five chapters of the current study, including study purpose, questions, methods, results, discussion, implications, and recommendations.

According to the Social-Ecological Model, factors that influence ACP engagement can be conceptually categorized into intrapersonal, interpersonal, and community factors (McLeroy et al., 1988). The published research that examined factors
influencing ACP engagement is limited in terms of recruiting older adult population solely, targeting minority racial populations without considering minority faith groups, using cross-sectional research design, lacking using theoretical/conceptual frameworks, and lacking reliable, valid tools to measure the influential factors. Additionally, findings regarding the associations between ACP engagement and other contextual factors vary in the published studies with some inconsistencies.

Common intrapersonal factors discussed in the literature were sociodemographic characteristics, health status, EOL experience, knowledge about ACP, and attitudes toward ACP. Overall, the literature has supported that the prevalence and the likelihood of engagement in ACP are associated with: older age, female gender, White race, income, education, poor health condition, chronic diseases, history of receiving medical treatment that could be provided for at the EOL, loss of a loved one, awareness of ACP, knowledge about ACP, and attitudes toward ACP.

Two interpersonal factors were commonly examined in the literature for their effect on ACP engagement: social support and acculturation. Social support was associated with a greater ACP engagement, but some studies observed no association or a negative association. Acculturation has been associated with ACP engagement and with increased awareness and knowledge, and positive attitudes towards ACP. Common community factors that might influence engagement ACP have been conceptualized into “community norms,” and “communication and decision-making styles.” Holding positive beliefs about ACP leads to higher engagement. Adapting autonomy decision-making style was associated with more engagement in ACP.
The purpose of this study was twofold: (1) to understand ACP engagement in a sample of Muslim community-dwelling adults living in the United States, and (2) to explore determinants of their ACP engagement. Through the lens of the Social-Ecological Model of McLeroy et al. (1988), potential ACP determinants were conceptualized into intrapersonal, interpersonal, and community factors. Advance care planning activities that were measured in the current study were: (1) completion of an ACP formal document, (2) designation of a health care proxy, (3) holding discussions with family or substitute decision-maker about medical treatment preferences, and (4) holding discussions with a healthcare provider about type of medical treatments preferred at EOL.

The following research questions were addressed:

1. What are the ACP engagement behaviors engaged among Muslim community-dwelling adults living in the United States?

2. What intrapersonal factors were associated with the ACP engagement among Muslim community-dwelling adults living in the United States?

3. What interpersonal factors were associated with the ACP engagement among Muslim community-dwelling adults living in the United States?

4. What community factors were related to the ACP engagement among Muslim community-dwelling adults living in the United States?

5. What combination of intrapersonal, interpersonal, and community factors were associated with ACP engagement among Muslim community-dwelling adults living in the United States?
6. What were the differences between age and gender groups regarding ACP engagement among Muslim community-dwelling adults living in the United States?

A cross-sectional correlational design was utilized in this study. The benefit of this design was its flexibility to enable researchers to assess the current situation and identify potential associations. The sampling techniques applied in the current study were convenience and snowball sampling. The target population in this study was Muslims living in the United States, but the accessible population was Muslims residing in N.C. Inclusion criteria were: (1) self-identified as a Muslim, (2) lived in the United States for at least one year at the time of recruitment, (3) age eighteen years or older, and (4) able to read, write, and comprehend English. Study participants were recruited from major Islamic organizations. The PI, as well as community insiders announced the study, posted, and distributed the study flyer at the proposed recruitment sites. In addition, the recruitment sites were encouraged to announce the study using their communication platforms. Based on G*Power calculations of linear regression, a sample size of 122 was determined to provide a statistical power of ≥ 80%, assuming a type I error rate of 0.05, an effect size of Cohen’s $f^2 = 0.15$, and 5% missing data (G*Power version 3.1.9.3).

A self-administered questionnaire was the data collection method. The survey was distributed in printed and electronic form. The study survey consisted of items that operationally assessed the study outcome construct (ACP engagement) as well as the constructs of the three levels of SEM (intrapersonal, interpersonal, and community factors). The following tools were used: Advance Care Planning Engagement Survey
(ACPES-4) (Sudore, Heyland, Barnes, et al., 2017), Sociodemographic form, single-item global self-rated health (CDC, n.d., Idler & Benyamini, 1997), six dichotomous yes-no EOL experience questions (Amjad et al., 2014), six-item knowledge subscale of the ACPES (Sudore et al., 2013), Decisional Balance Scale (Fried et al., 2012), Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988), Acculturation Scale for Muslim Americans (Bagasra & Mackinem, 2019), ACP Values/Belief scale (Fried et al., 2012), and Control Preferences Scale (Degner, Sloan et al., 1997).

Approval for the study was obtained from the Institutional Review Board (IRB) of the University of North Carolina Greensboro. An information sheet was attached to the survey. Multiple measures were enacted to ensure participants’ anonymity and data confidentiality.

The sample was comprised of 148 Muslim adults. Thirty-nine participants completed the printed copy of the questionnaire, and 109 participants used the online survey. Participants’ age ranged from 18 to 79 years old, and the mean age was 36.7 years. The majority of participants were living in North Carolina, were married, were immigrants, self-identified from three racial minority groups (Asian, Black, and Middle Eastern or North African), were employed, reported having at least good health status, had at least $35,000 of household income, and reported having had at least one previous decision-making and EOL experience. The active role was the most common preferred decision-making style.
The participants’ engagement in any of the ACP activities was low. About two-thirds of participants were identified in precontemplation stage of change of engagement in ACP activities because they reported no thinking or readiness to engage in any ACP activities. Low proportions were in action or maintenance stages. Few persons had signed official advance directives, designated a health care proxy, documented their EOL medical preferences, discussed EOL medical preferences with a decision-maker, or discussed EOL medical preferences with a healthcare provider.

There were no age or gender differences in ACP engagement. Persons who had poor/fair health, had major surgery, had a serious illness, had heard about ACP, had made a decision before, knew a deceased person who received aggressive or minimal treatments, or knew a person who had declared EOL preferences had a significantly higher engagement in all ACP activities compared to their counterparts.

The findings indicated that ACP engagement was positively associated with the length of time living in the United States, conformity to American culture, having ACP knowledge and awareness, being married, being nonimmigrant, being Asian, being employed, or having had any decision-making and EOL experiences. Negative associations were found between ACP engagement and adherence to Islamic culture, being Middle Eastern, having an income lower than $50,000, or having a better health status. Advanced care planning engagement was predicted by several intrapersonal and interpersonal factors but not by any of the community factors. The ACP engagement was higher in those who were born in the United States, who self-identified as Asian American, who had awareness of ACP, who knew a deceased person who had received
aggressive EOL medical treatments, who had knowledge about ACP, and who reported
greater conformity to American culture. However, ACP engagement decreased for those
who knew a deceased person who received minimal EOL medical treatments.

A substantially low prevalence of ACP engagement was indicated in this study
when compared to overall prevalence of ACP engagement in the US. Similarly, the
prevalence of ACP engagement among Muslim population found in this study is lower
than that has been estimated in any previous study that included any race- or faith-
minority populations (Ko & Berkman, 2012; Ko & Lee, 2014; Rahemi et al., 2019; Rao
et al., 2014; Yadav et al., 2017).

In the current study, Asian Americans had greater ACP engagement than their
White counterparts. This finding is similar to Carr (2012) but is inconsistent with other
studies that found lower ACP engagement among minority populations compared to
Whites (Choi et al., 2018; Orlovic et al., 2019). Although some studies found that race
was a factor in the engagement in ACP, those that controlled for the influence of other
variables found that race alone is not a determinant factor in the level of engagement in
ACP (Choi et al., 2018; Ko & Lee, 2014; McAfee et al., 2019). This finding suggests that
additional research is warranted to explore to what extent race can predict engagement in
ACP.

In this study, the self-reported health status was negatively associated with ACP
engagement, which is similar to findings observed in previous research (Carr, 2012; Choi
et al., 2018; Musa et al., 2015). In this study, people who had a serious illness were more
likely to engage in ACP engagement, which is consistent with other previous studies
Being a nonimmigrant was a determinant of ACP engagement. This could be explained by that non-immigrants might be more knowledgeable and aware of ACP than those who were immigrants (Eckemoff et al., 2018). Consistent with Amjad et al. (2014), having an experience of knowing a deceased person who received aggressive or minimal EOL treatments was related to ACP engagement. Experience with aggressive treatment was associated with increase in ACP and experience with low medical treatment was associated with low engagement.

The reported average scores of attitudes toward ACP and community norms held by the sample indicated acceptance of ACP, which is congruent with attitudes and norms held by other populations and Islamic teachings (Duffy et al., 2006; Ingravallo, 2018; Lee et al., 2016; McAfee et al., 2019). The study finding that community norms and attitudes toward ACP did not predict ACP engagement is contradicting with findings from previous research (Ko & Lee, 2014; McAfee et al., 2019; Rahemi, 2017). It seems that norms and attitudes toward ACP held by our sample reflect the Islamic law perspective, which appears to be congruent with ACP (Al-Jahdali et al., 2013). Similarly, adopting the American culture was associated positively with the participants’ engagement in ACP. A similar finding that greater acculturation was associated with a higher likelihood of engagement in ACP was also found among Korean Americans and Latinos (Dobbs et al., 2015; Kelley et al., 2010).

This study addressed several knowledge gaps. First, the findings increased our knowledge about ACP engagement among young adults living in the US. Second, these findings provided fundamental knowledge about ACP engagement among Muslims.
living in the US. Third, this study expanded the body of knowledge regarding ACP among faith-communities in the US. Fourth, this study measured multiple ACP activities. Fifth, this study contributed to the current knowledge about the associations between engagement in ACP and other contextual factors in addition to the combined effect of these factors on ACP engagement. Sixth, this study used reliable and valid tools to measure engagement ACP and the potential contributing factors.

The findings of this study suggest several essential implications. The study supported research conclusions about disparities in ACP engagement among the American population. Lack of ACP engagement might contribute to the fact that the Muslim population’s EOL medical preferences and wishes are unknown to health care workers. The disparity in ACP engagement among Muslims living in the US were associated with several intrapersonal and interpersonal factors. However, there were some intrapersonal and interpersonal factors, as well as all the community factors that we measured that did not account for any disparities in ACP engagement. These findings reflect the uniqueness of ACP behavior in the Muslim community that implies a need for unique and tailored strategies to deal with a lack of engagement in ACP.

The findings showed a need for nursing education regarding culturally competent strategies for providing care while considering contextual factors such as awareness, knowledge, acculturation, and past experiences with EOL. The American Nurses Association (ANA) recommends several nursing roles regarding ACP. Nursing roles in ACP include, but are not limited to, facilitating ACP conversations, participating in ACP conversations, helping with preparing the ACP documents, participating in maintaining
these documents, advocating for ACP, and providing ACP education for the public (ANA, 2017). Nurses and other health care providers should be proactive by providing information about ACP for Muslims in both hospital and community settings. Information about ACP provided should be culturally and religiously appropriate. Nurses should be prepared through education and training in terms of being culturally competent and person- and family-centered. Therefore, nursing professors and educators should incorporate findings from transcultural ACP studies, like this study, in order to prepare nurses for practice within a culturally diverse health care settings and to assess and intervene for EOL care needs.

There is a need for increasing public knowledge and awareness about ACP. One method that can reduce health disparities is creating community coalitions (Anderson, Adeney, Shinn, Krause, & Safranek, 2012; CDC, 2011). Cohen et al. (2002) defined a coalition as “a union of people and organizations working to influence outcomes on a specific problem” (p. 144). Coalitions involve representatives of the target minority group to plan and implement interventions for community-level change (Anderson et al., 2012). Across the US, coalitions show benefits for a wide range of communities (CDC, 2011). Therefore, establishing a coalition to support interventions addressing disparities in engagement in ACP among the Muslim population could be beneficial. This coalition would include people from different public parties in the Muslim community, such as clinicians, commercials, industries, schools, academia, government, political, and the faith community. The advantages of including all of these parties might be the
development of culturally sensitive interventions and raising funding resources for ACP research.

Findings from this study indicate that the current health policies that regulate ACP should be revisited, or new policies should be enacted. Several federal policies have been enacted to improve engagement in ACP. Examples of such policies are the Patient Self-Determination Act (PSDA), the Patient Protection and Affordable Care Act (PPACA), and the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. The PSDA has considered respecting patients’ autonomy by activation procedures and policies to facilitate their participation in making decisions regarding EOL medical treatments. The PPACA focused on improving the quality of EOL care and reforming payment for EOL care services (Parikh & Wright, 2017). The RAISE Family Caregivers Act of 2017 has stressed addressing caregivers’ educational needs regarding palliative and hospice care and ACP. Currently, all the U.S. states and the District of Columbia have issued legislation that organizes the implementation of a durable power of attorney within the healthcare organizations (American Bar Association, 2018; IOM, 2015). Despite these policies and regulations, the current study findings suggest that the current ACP policies have failed to mitigate disparities in ACP engagement among minority populations. These findings are consistent with the previous research that found low ACP engagement among minority populations such as race/ethnic minorities, veterans, LGBT, disabled, and rural-dwellers (Wicks et al., 2018). Indeed, the wishes and preferences of minority communities might not be recognized at the end of their lives, making the quality of EOL care questionable (Wicks et al., 2018).
Nurses should be involved in revising and evaluating ACP policies that affect not only patients’ and their families’ outcomes, but the entire nursing staff who are involved in patient-related healthcare issues (Burke, 2016). The current ACP policies are limited in terms of assuming that all healthcare providers have sufficient training to discuss ACP with patients and their families. However, previous evidence has shown that many providers reported having stress and difficulty in initiating conversations with people about topics related to ACP, and many of them believe that they are not well-trained to do this task as well (Frontera et al., 2015; Thomas, Zubair, Hayes & Ashby, 2014). Additionally, the current ACP policies focus on access for ACP for Medicare and Medicate beneficiaries. However, these policies have never considered ACP access for Americans who have limited access to health care or those who have health care plans that do not cover ACP conversations.

Nurses are also involved in the multidisciplinary professional organizations that intend to enforce health policies that facilitate patients’ engagement in ACP. For example, nurses who collaborate with their colleagues in the National Coalition for Hospice and Palliative Care (NCHPC), which is a multidisciplinary collaborative partnership, have helped influence policy changes that have improved the care of people with life-limiting diseases by submitting reports and comments to multi legislative institutions (NCHPC, 2018). Some of these letters consider ACP policies. One of these letters was submitted to the CMS and has addressed issues in CMS’s policy of reimbursement for ACP (NCHPC, 2015).
Based on the findings from this study, several recommendations are suggested for future research. Investigate further the association between engagement in ACP and intrapersonal, interpersonal, and community factors among Muslims and other minority faith populations. Conduct studies that investigate ACP knowledge and attitudes among the Muslim population in order to formulate a knowledge base for future interventions. Discover culturally and religiously appropriate methods to improve ACP knowledge and awareness. Explore practical strategies to facilitate informal ACP discussions between Muslim adults and their loved ones, and formal ACP discussions between Muslim adults and families, and health care providers. Examine ACP engagement behavior among older adults as well as young adults. Examine ACP as a multi-activity behavior instead of an act of only signing official papers. Apply conceptual frameworks to guide studies that investigate ACP engagement behavior. Utilize reliable and valid structured tools when measuring ACP engagement and its contributing factors. Increase funding for ACP research might help to address the reasons behind the low engagement rate in ACP discussions among the general population and marginalized communities.

In summary, engagement in ACP is a multifactorial behavior. Therefore, a unidimensional intervention or policy will never adequately address disparities in ACP activities. In addition to nurses, health care professionals, social workers, clergy, and community leaders should intervene collaboratively to support practicing ACP in faith communities.
REFERENCES


Retrieved from
http://www.oxfordhandbooks.com/view/10.1093/oxfordhb/9780195326246.001.0
001/oxfordhb-9780195326246-e-9

*Encyclopedia of Aging and Public Health.* Springer, Boston, MA. Retrieved from
https://link.springer.com/referenceworkentry/10.1007%2F978-0-387-33754-
8_72#howtocite

https://www.cair.com/islam_basics

Cruz-Oliver, D. M., Talamantes, M., & Sanchez-Reilly, S. (2014). What evidence is
available on end-of-life (EOL) care and Latino elders? A literature review.
*American Journal of Hospice and Palliative Medicine®, 31*(1), 87–97.

ethical decisions in a neonatal intensive care unit in a Muslim community.
doi:10.1136/fn.86.2.F115

perceived social support: A confirmation study. *Journal of Clinical Psychology,
47*(6), 756–761.


role in end-of-life decision making. *BMC Palliative Care, 17*(1), 29.

conflict to advance directives attitude in Korean older adults: A community-based
doi:10.1111/jjns.12081

in advance care planning: A community-based, culturally sensitive seminar.
*Journal of Gerontological Nursing, 41*(8), 17–21. doi:10.3928/00989134-20150406-01

directives and advance care planning in Chinese people from Eastern and Western
cultures. *Journal of Hospice & Palliative Nursing, 16*(2), 75–85.
doi:10.1097/NJH.0000000000000024

*Palliative Medicine, 28*(8), 1026–1035. doi:10.1177/0269216314531313


considerations on the application of patient’s autonomy in end-of-life decision.


doi:10.1016/S8755-7223(00)80008-3


https://polst.org/polst-advance-care-planning/


Communication tools for end-of-life decision-making in ambulatory care settings:
doi:10.1371/journal.pone.0150671

Orlovic, M., Smith, K., & Mossialos, E. (2019). Racial and ethnic differences in end-of-
life care in the United States: Evidence from the Health and Retirement Study

http://www.oxfordislamicstudies.com/article/opr/t125/e2427


Psychometric characteristics of the multidimensional scale of perceived social support. *Journal of Personality Assessment, 55*(3-4), 610–617.