



Advance Care Planning Engagement Among Muslim Community-Dwelling Adults Living in the United States

Ghaith A. Bani Melhem, PhD, MSN, RN ○ Debra C. Wallace, PhD, RN, FAAN ○
Judith A. Adams, PhD, MSN, RN, FNP-BC ○ Ratchneewan Ross, PhD, RN, FAAN ○
S. Sudha, PhD

Advance care planning (ACP) is a cornerstone of self-determination for the type of care provided at the end of life. Despite many national efforts to improve American adults' engagement in ACP, statistics indicate low engagement. Low engagement, especially among racial and ethnic minority populations, immigrants, people with lower socioeconomic status, young adults, rural residents, or non-English speakers, is common. Advance care planning engagement among Muslims living in the United States has been minimally studied. The purpose of this study was to explore Muslims' engagement in ACP. A cross-sectional descriptive design was used. Participants were recruited from Islamic organizations through convenience and snowball sampling. Engagement in ACP was measured by the Advance Care Planning Engagement Survey. A sample of 148 Muslims (18-79 years of age) participated in the study. The average engagement scores ranged from 1.97 to 2.09, with about two-thirds in the precontemplation stage. Significant differences in engagement scores were found according to health condition and end of life experiences. Results suggest a need for further collaborative efforts by health care providers, policymakers, and researchers to mitigate the disparities in ACP engagement in the American Muslim community.

KEY WORDS

advance care planning, decision-making, disparity, end of life, health behavior, Islam, minority, Muslims, palliative care, race, transtheoretical model

End of life (EOL) treatment decisions were historically informal in the United States until the passage of the Patient Self-determination Act that required health care facilities funded by Medicare to provide written documents that exhibit patients' right to participate in making decisions.¹ The Institute of Medicine has endorsed advance care planning (ACP) as a process that facilitates decision making at EOL of seriously ill Americans.² Similarly, palliative, hospice, and EOL care organizations have supported ACP for seriously ill people.^{2,3}

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."⁴ Engaging in ACP allows individuals and family members to explore, discuss, and communicate their values, beliefs, and preferences for health care in the event that they become incapable of communicating.^{2,5} For people who were at the end of their lives, engagement in ACP has been associated with reduction in receiving of unwanted life-sustaining 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, higher compliance with following patients' preferences, higher family and patient satisfaction, and high quality of both life and death.^{2,3} No one typical action corresponds to ACP.^{5,6} 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 the patient's preferences regarding life-sustaining medical treatment with family and/or health care professionals, and (4) discussion of the patient's preferences regarding quality versus quantity of life with family and/or health care professional.^{6,7}

Although ACP activities involve discussions about EOL issues, these discussions may occur at any stage of the life,

Ghaith A. Bani Melhem, PhD, MSN, RN, is lecturer, Royal Medical Services College for Allied Health Professions, Al-Balqa Applied University, Amman, Jordan.

Debra C. Wallace, PhD, RN, FAAN, is professor, Department of Family and Community Nursing, University of North Carolina at Greensboro.

Judith A. Adams, PhD, MSN, RN, FNP-BC, is assistant professor, School of Nursing, University of North Carolina at Greensboro.

Ratchneewan Ross, PhD, RN, FAAN, is professor, School of Nursing, University of North Carolina Greensboro.

S. Sudha, PhD, is associate professor, Department of Human Development and Family Studies, University of North Carolina Greensboro.

Address correspondence to Ghaith A. Bani Melhem, PhD, MSN, RN, Royal Medical Services College for Allied Health Professions, Al-Balqa Applied University, Amman, Jordan (melhembani1981@gmail.com).

The authors have no conflicts of interest to disclose.

Copyright © 2020 by The Hospice and Palliative Nurses Association. All rights reserved.

DOI: 10.1097/NJH.0000000000000690



not just at the EOL.⁴ Recommendations are that all adults should be engaged in ACP conversations, regardless of their age, sex, race, or health status.^{2,4} However, a meta-analysis of findings published from 2011 to 2016 had estimated the ACP engagement rate among community-dwelling American adults as only 36.7%.⁸

Disparities in the rate of ACP engagement exist, with a substantial low rate of engagement among racial and ethnic minority populations, immigrants, rural residents, or non-English speakers.⁸⁻¹¹ Furthermore, findings from ACP research showed that engagement in ACP varies according to age, sex, health status, and self-experienced or witnessed EOL treatments.⁹⁻¹² Indeed, the existing evidence on ACP disparities has revealed significant variations in the quality of EOL care and death across all the groups.²

Reviews of the literature on age and sex differences in ACP engagement revealed that the older age groups and women were more likely to engage in ACP than their counterparts.^{9,13} However, there has been a little exploration of ACP engagement among healthy young adults. As of 2019, there were only 3 published studies that examined ACP engagement among healthy young adults.¹⁴ The findings of studies of knowledge and engagement in ACP showed that only 2% of young American adults reported having an ACP document.^{14,15} Research findings regarding sex differences in ACP engagement vary. Several studies found that women were significantly more likely to engage in any of ACP activities than men.^{10,12,13} However, no significant sex differences in ACP engagement was found in another study.¹⁴

Self-reported health status plays a critical role in engagement in ACP. Overall, poor health status was associated with higher engagement in ACP.¹³ For example, a study of 1823 British older adults (≥ 65 years) revealed that British older adults who reported better health status were 40% less likely than their counterparts to complete ACP documents.¹²

Having a past self-experience of EOL treatments was associated with a better readiness to engage in ACP.^{16,17} A cross-sectional descriptive study that included 304 older adult Americans (≥ 60 years) found that living with a life-limiting disease or having a past personal experience of an intensive medical treatment was positively associated with increased willingness to engage in ACP discussions.¹⁷ Being a witness to others' EOL experiences was positively associated with a higher engagement in ACP.^{17,18} A cross-sectional quantitative study of 304 American older adults revealed 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.¹⁷

The research in ACP in minority groups to date has tended to focus on racial rather than faith minority groups. Thus, few primary published research projects have studied the ACP topic among faith communities in the United

States. One of the minority faith communities in the United States is the community of the followers of Islam, or Muslim Americans. 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.¹⁹ Most Muslim Americans (58%) are immigrants with a variety of racial and ethnic backgrounds, languages, and national origins.²⁰ Although most (41%) 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 Black Muslims converted to Islam.^{20,21} Islam is the shared unified religion that informs the life affairs, belief systems, and behaviors of these diverse populations.²⁰ The Muslim American community has the youngest median age (24 years) in the United States.²² However, it has been projected that by 2030, the number of Muslim American seniors will increase from 140 000 to 570 000, which implies a growing need for Muslim Americans to engage in ACP.²²

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

CONCEPTUAL FRAMEWORK

To describe ACP engagement according to different stages, this study used the Trans-Theoretical Model of Change (TTM).²³ The TTM posits that people transit through a step-ladder process of stages to change a current behavior or adopt a new one.²³ The stages of change model is useful in understanding a person's engagement or readiness to engage in ACP.⁶ According to this model, the stages of change include precontemplation, contemplation, preparation, action, and maintenance.⁶ A person who has no interest to engage in ACP would be considered in the precontemplation stage of change, whereas 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 engagement in ACP is considered being in the action stage if it started within 6 months and in the maintenance stage if it continued to 6 months or greater.^{6,7,23,24}

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. The 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. Procedures used 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.

Measures

A structured self-reported survey was used. The survey consisted of questions about demographic characteristics in addition to items that operationally assessed ACP engagement, health status, ACP awareness, and experiences with decision making and EOL 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.²⁵ Past EOL treatment experience was assessed by 6 dichotomous yes-no questions.¹⁷

ACP ENGAGEMENT

The 4-item version of the Advance Care Planning Engagement Survey (ACPES-4) was used to measure ACP engagement.²⁴ The tool was developed based on Prochaska's TTM and has become a valid and reliable tool to measure adults' engagement in ACP.^{24,26} The tool's developers estimated Cronbach α coefficient at .86.²⁴ The overall average score of ACPES-4 could range from 1 to 5, with 5 indicating the highest 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).²⁴ According to their ACPES-4 responses for each ACP activity, participants were classified into 5 groups

of behavior change: precontemplation (scores 1 and 2), contemplation (score 3), preparation (score 4), action (score 5 and action was done within 6 months), and maintenance (score 5 and action was done ≥ 6 months ago).

Procedure

The principal investigator and 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 survey was provided through printed copies, or digital copies using Qualtrics software. People who were recruited in person were provided the opportunity to have a printed copy of the survey as well as a stamped envelope to be mailed back after completion. The questionnaire was piloted with 5 people, and the time to complete the printed version was 20 to 25 minutes; the time to complete the online version was 15 to 25 minutes.

Human Subjects Protection

The study was qualified for expedited review category by the institutional review board of the university. The information sheet at the beginning of the survey included the principal investigator contact information and explained the study timing, risks, and strategies to minimize breaches of confidentiality. All measures that protect data confidentiality were maintained. A \$10 electronic gift card was offered to each person who participated in the study.

Statistical Analysis

Univariate statistics were used to describe the sample and to answer the first research question. Frequency, percentage, central tendency measures (mean), and variability index (standard deviation) were used to summarize sociodemographic characteristics, health status, decision making and EOL experiences, and self-reported engagement in any of the 4 ACP activities, as well as stages of change for ACP engagement. Mann-Whitney *U* tests were used to answer the second research question. All Mann-Whitney *U* test assumptions were met, including that the measured variables were not normally distributed. All analyses were performed using SPSS v26.²⁷ A 2-sided *P* value $< .05$ was considered statistically significant.

RESULTS

Sociodemographic Characteristics

Printed copies of the survey were returned within 4 weeks. Online surveys were received within about 5 weeks. The sample comprised 148 Muslim adults, with 39 completing



TABLE 1 Sample Description (N = 148)

Characteristics	n (%)
Sex ^a	
Males	85 (57.4)
Females	62 (41.9)
Living in NC	
Yes	104 (70.3)
No	44 (29.7)
Born in the United States	
Yes	56 (37.8)
No	92 (62.2)
Country of origin ^b	
Asia	33 (22.3)
Africa	11 (7.43)
Arab countries	71 (47.97)
United States	16 (10.81)
Other	13 (8.78)
Native language ^c	
English	30 (20.2)
Arabic	68 (45.3)
Urdu	16 (10.8)
Hausa (Africa)	5 (3.4)
Other	19 (12.8)
Marital status	
Married	97 (65.5)
Unmarried	51 (34.5)
Race/ethnicity	
Asian	34 (23.0)
Black or African American	18 (12.2)
Middle Eastern or North African	54 (36.5)
White	34 (23.0)
Other race/ethnicity	8 (5.4)
Health status	

(continues)

TABLE 1 Sample Description (N = 148), Continued

Characteristics	n (%)
Poor	2 (1.4)
Fair	25 (16.9)
Good	53 (35.8)
Very good	47 (31.8)
Excellent	21 (14.2)
Hearing about ACP	
Yes	78 (52.7)
No	69 (46.6)
Age in years, mean ± SD	36.7 ± 13.141
Abbreviations: ACP, advance care planning; NC, North Carolina. ^a Data missing for 1 participant. ^b Data missing for 4 participants. ^c Data missing for 10 participants. ^d Data missing for 6 participants. ^e Data missing for 5 participants.	

the survey in person and 109 completing the survey online. Most participants lived 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, with a mean (SD) age of 36.7 (13.14) years. Approximately two-thirds of the sample (65.5%) reported being married (see Table 1).

Most (62.2%) of participants were immigrants having lived in the United States for an average of 16 years (SD, 1.04 years). 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 most (77%) self-identified from 3 racial minority groups (Asian, Black, and Middle Eastern/North African). The most common self-reported employment status was either working full- or part-time (63.5%). Approximately two-thirds of the sample reported having a household income of at least \$35 000. About one-fifth of the participants (18.3%) reported having a poor or fair health status.

Advance Care Planning Awareness

Participants' awareness of ACP was assessed by 1 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.



ACP Engagement

The ACPES-4 showed excellent internal consistency reliability, with a Cronbach's α coefficient of 0.86. 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 1 ACP activity, and 5 (3.4%) reported engagement in all ACP activities, including executing ACP official documents and conducting ACP discussions. About one-seventh (14.9%) of participants had signed ACP official papers, with 8.8% having a designated health care proxy and 6.1% having documented their EOL medical preferences and wishes. Fewer 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 health care provider.

The distribution of participants on stages of change for all ACP activities is presented in Table 3. Most (about two-thirds) were in precontemplation stage of change, reporting no readiness to engage in 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 10 of the 148 participants were considering signing papers designating a decision-maker substitute in the near future.

Overall, the trends of the participants' distribution on the 5 stages of change of ACP engagement were unequal. Compared with other stages of change, the earliest stage of change, which is the precontemplation stage, included the

highest number of participants. For instance, whereas 72.2% of participants were in the precontemplation stage for signing ACP official documents, 6.1% were the action and maintenance stages. The number of participants who were in the contemplation stage was low for ACP activities. Interestingly, equal numbers of participants were in the contemplation stage of 3 ACP activities: conducting informal discussions about EOL care preferences, conducting formal discussions about EOL care preferences, and signing papers putting wishes about the kind of medical care preferred in future.

Decision Making and EOL Experiences

Participants' decision-making and EOL experiences are presented in Table 3. Two-thirds of the sample (65%) reported having at least 1 previous experience with EOL. Fewer 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 1 experience related to other people's EOL medical treatments or decision making. The most frequently reported EOL care-related experiences were knowing a person who had a bad death because of either receiving aggressive or receiving minimal medical treatments; 37.8% of the participants reported at least 1 EOL experience.

The results of research question 2 are provided in Table 3. Overall, no significant differences were found between participants regarding engagement in any given ACP activity according to sex and age. However, significant differences existed between groups of people reported having ACP awareness, experience of illness, surgery, decision making, or EOL treatment compared with other groups who denied

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

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

Abbreviations: A, action stage of change; ACP, advance care planning; C, contemplation stage of change; EOL, end of life; M, maintenance stage of change; PC, precontemplation stage of change; PR, preparation stage of change.

^aData missing for 1 participant.

^bData missing for 2 participants.



TABLE3 ACP Engagement Score Differences Among Participants (N = 148)

ACP Activity Characteristics	Decision-Making Substitute				Informal EOLDiscussions				Formal EOL Discussions				EOL Preferences Determination			
	n	M	P	U	n	M	P	U	n	M	P	U	n	M	P	U
Sex			.522	275			.307	280			.414	275			.229	284
Female	62	1			61	1			61	1			61	1		
Male	84	2		5	84	2		0	84	2		2	84	2		0
Age			.071	301			.512	416			.429	403			.552	423
<60 y	139	72 ^a			138	74 ^a			138	74 ^a			138	73 ^a		
≥60 y	7	100 ^a			7	64 ^a			7	62 ^a			7	64 ^a		
Heard about ACP			<.001	1326			<.001	1085			<.001	1322			<.001	858
Yes	77	2.4			76	2			77	2			77	2		
No	69	1			69	1			68	1			68	1		
Health status			<.001	927			.001	986			.001	980			.002	987
Poor/fair	27	3			27	3			26	3			26	2.4		
Good-excellent	120	1			119	1			120	1			120	1		
Had a serious illness			.013	1560			.003	1422			.001	1375			<.001	1269
Yes	39	2			38	2.4			39	2			39	2		
No	107	1			107	1			106	1			106	1		
Had a major surgery			<.001	1486			.005	1693			<.001	1497			<.001	1502
Yes	48	2			47	2			47	2			47	2		
No	99	1			99	1			99	1			99	1		
Had a decision-making experience			<.001	1002			<.001	862			<.001	809			<.001	672
Yes	39	3			38	3			39	3			39	3		
No	108	1			108	1			107	1			107	1		
Know a deceased one received ATs			.002	1816			<.001	1506			<.001	1336			<.001	1492
Yes	55	2			55	2			55	2			55	2		

(continues)

**TABLE3** ACP Engagement Score Differences Among Participants (N = 148), Continued

ACP Activity Characteristics	Decision-Making Substitute			Informal EOL Discussions			Formal EOL Discussions			EOL Preferences Determination		
	n	M	P	U	n	M	P	U	n	M	P	U
No	92	1			91	1			91	1		
Know a deceased one received MTs			.009	1916			.015	1939			.019	1960
Yes	55	2			55	2			55	2		
No	92	1			91	1			91	1		
Know a person declared preferences			<.001	1236			<.001	1349			<.001	1118
Yes	46	3			46	3			46	3		
No	101	1			101	1			100	1		

U represents Mann-Whitney U test.

Abbreviations: ACP, advance care planning; ATs, aggressive treatments; EOL, end of life; M, median; MTs, minimal treatments.

^aRank values.

having these kinds of experiences. Those who had poor/fair health, had a 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's declared EOL preferences had a significantly higher distribution of engagement in all ACP activities compared with their counterparts.

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 sex, age, health status, and experiences with EOL medical treatments and decision making that are associated with engagement.

This study found that about one-half of the participants reported a lack of awareness of ACP. This finding is consistent with other findings of ACP studies that targeted racial and ethnic minority populations.^{16,28,29} Lack of awareness of ACP among minority populations could be explained by immigration status, the length of residency, and acculturation.^{16,28,29} In this line, a cross-sectional study found that immigrant Russian Americans have lower ACP awareness than their nonimmigrant counterparts.²⁸ The likelihood of being aware of ACP increased among Chinese Americans who had higher acculturation and lived in the United States for at least 20 years.¹⁶

Surprisingly, Muslims' engagement in any of ACP activities, including executing official ACP documents and conducting both formal and informal ACP discussions, was relatively lower than that of any other minority population in the United States.⁸⁻¹¹ Furthermore, the rate of engagement in any of ACP activities revealed in this study is substantially lower than what was estimated in studies that included only young people.^{14,15} One exception was the rate of engagement in formal ACP discussions. Although the rate of engagement in formal ACP discussions was estimated at 7.4% in this study, it was reported at 2% in previous studies.^{14,15} However, the rate of engagement in informal ACP discussions in this study was substantially lower than the rate reported in previous studies of American young adults.^{14,15,18}

The findings of this study demonstrated that most 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 and maintenance stages). The low number of participants in the action and maintenance stages (13%) indicates a substantially low rate of ACP engagement in Muslim American community, when compared with the overall US national rate of ACP engagement, which has been estimated at 36.7%.⁸ Similarly, the rate 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.^{10,30,31} 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.³¹ Another American study found that one-fifth of a sample of racially diverse older adults (Whites, African Americans, and Hispanics) reported having an ACP official document.³⁰

Although exploring the reasons behind the low rate of engagement in ACP was beyond the scope of this study, probable explanations might be suggested. One possible explanation is that most Muslims in the United States are immigrants from countries without ACP services. Results of several studies of ACP in Islamic countries indicate that ACP documents were minimally provided there.^{32,33} Environmental and social barriers, such as health literacy, lack of English proficiency (17% of the Muslim Americans are non-English speakers), system distrust, health care access, or other perceived barriers might lead to limited engagement in ACP.¹¹ In addition, current ACP-related policies have supported ACP access for only Medicare and Medicaid beneficiaries; however, such policies do not include ACP access for Americans who have no health care insurance or for those who have health care insurance plans that do not cover ACP conversations.

The substantially low prevalence of ACP engagement among the study sample might indicate that the study participants were unaware of the Islamic teachings regarding the ACP and EOL-related issues. Islam teaches Muslims to expect death at any time and encourages conversations about death.³⁴ 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 ye be brought back."³⁴ In addition, Islamic teachings are consistent with the self-determination principle of the ACP.^{32,35} Based on a story that happened in the era of the Prophet Mohammad (peace be upon him), Muslim scholars concluded that (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.³² Based on the mentioned Islamic teachings, the Islamic Medical Association of North America has recommended that all Muslims should have ACP documents.³⁵

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 in older adulthood.^{9,10,12,36} For example, of a representative sample of 7946 American adults, 51.2% of adults older than 65 years had executed an advance directive compared with only 11.8% of those younger than 34 years old.¹⁰ On the other hand, the finding of absence of ACP engagement differences between age groups is consistent with the finding of Rahemi and

colleagues³¹ study, which demonstrated no association between age and engagement in ACP among Iranian Americans, including Muslims. Unlike most studies in ACP literature, which involved older adults, this study included a low number of older adults, which could explain no significant difference in ACP engagement between age groups.

This study finding of no sex difference in engagement in any of ACP activity is consistent with some ACP studies^{14,31} but contradicts other ACP studies that found a greater ACP engagement among women than men.^{10,13} The absence of either sex or age differences in engagement in different ACP activities could be explained by the overall low rate of ACP engagement. Another potential explanation is the typical method of making decisions in Muslim communities. Unlike the American norm of individualism and self-determination, Muslims usually define themselves as a relative part of their families.³⁷ A family-centered decision-making style is followed by Muslims worldwide.³⁸ Furthermore, Muslims may ask for advice from imams (Muslim religious scholars) at the time of decision making.³⁸ Thus, regardless of sex and age, different parties, including family, relatives, and imams, may participate actively in the decision-making process. 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 indicate 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.^{12,13} Having had decision-making and EOL experiences was associated with a higher level of ACP engagement among the study participants. Similar findings were found in previous research. A study of Muslims in the United States found that having experienced the loss of a loved one was associated positively with engagement in EOL planning.³¹ Another study found that having a life-limiting illness was a motivator for considering ACP in a minority American population.³⁹

LIMITATIONS

The study has the following limitations: (1) because the US 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; (2) because we used convenience and snowball sampling 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; (3) using self-administered instruments that have not been used previously or validated in Muslims living in the United States could affect the data validity; and (4) the 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.

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, health care 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 the 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 additional states and large cities. 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. Efforts of the multidisciplinary collaborative partnerships such as the National Coalition for Hospice and Palliative Care should be supported to enact policies that mitigate disparities in ACP engagement.

CONCLUSION

Muslims' engagement in ACP activities was relatively low. Awareness of ACP 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. 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 the ACP activities.

References

- Teoli D, Ghassemzadeh S. Patient Self-determination Act. In: *StatPearls*. Treasure Island, FL: StatPearls Publishing; 2019. <https://europepmc.org>. Accessed July 30, 2020.
- Committee on Approaching Death: Addressing Key End of Life Issues, Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press (US); 2015.
- Coalition activities. National Coalition for hospice and palliative care website. <https://www.nationalcoalitionhpc.org>. Published 2018. Accessed December 1, 2019.
- Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage*. 2017;53(5):821-832.e1. doi:10.1016/j.jpainsymman.2016.12.331.
- Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol*. 2017;18(9):e543-e551. doi:10.1016/s14702045(17)30582x.
- Fried TR, Redding CA, Robbins ML, Paiva A, O'Leary JR, Iannone L. Stages of change for the component behaviors of advance care planning. *J Am Geriatr Soc*. 2010;58(12):2329-2336. doi:10.1111/j.1532-5415.2010.03184.x.
- Sudore RL, Heyland DK, Lum HD, et al. Outcomes that define successful advance care planning: a Delphi panel consensus. *J Pain Symptom Manage*. 2018;55(2):245-255.e8.
- Yadav KN, Gabler NB, Cooney E, et al. Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Aff (Millwood)*. 2017;36(7):1244-1251. doi:10.1377/hlthaff.2017.0175.
- McAfee CA, Jordan TR, Sheu JJ, Dake JA, Kopp Miller BA. Predicting racial and ethnic disparities in advance care planning using the integrated behavioral model. *Omega (Westport)*. 2017;30222817691286. doi:10.1177/0030222817691286.
- Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. *Am J Prev Med*. 2014;46(1):65-70. doi:10.1016/j.amepre.2013.09.008.
- Hong M, Yi EH, Johnson KJ, Adamek ME. Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: a systematic review of the current literature. *J Immigr Minor Health*. 2018;20(5):1277-1287. doi:10.1007/s10903-017-0670-9.
- Musa I, Seymour J, Narayanasamy MJ, Wada T, Conroy S. A survey of older peoples' attitudes towards advance care planning. *Age Ageing*. 2015;44(3):371-376. doi:10.1093/ageing/afv041.
- Choi S, McDonough IM, Kim M, Kim G. The association between the number of chronic health conditions and advance care planning varies by race/ethnicity. *Aging Ment Health*. 2020;24(3):453-463. doi:10.1080/13607863.2018.1533521.
- Schnur K, Radhakrishnan K. Young adult knowledge and readiness to engage in advance care planning behaviors. *J Hosp Palliat Nurs*. 2019;21(1):54-60. doi:10.1097/NJH.0000000000000487.
- Kavalieratos D, Emecoff NC, Keim-Malpess J, Degenholtz HB. Knowledge, attitudes, and preferences of healthy young adults regarding advance care planning: a focus group study of university students in Pittsburgh, USA. *BMC Public Health*. 2015;15:197. doi:10.1186/s12889-015-1575-y.
- Gao X, Sun F, Ko E, Kwak J, Shen HW. Knowledge of advance directive and perceptions of end-of-life care in Chinese-American elders: the role of acculturation. *Palliat Support Care*. 2015;13(6):1677-1684. doi:10.1017/S147895151500067X.
- Amjad H, Towle V, Fried T. Association of experience with illness and end-of-life care with advance care planning in older adults. *J Am Geriatr Soc*. 2014;62(7):1304-1309. doi:10.1111/jgs.12894.
- Tripken JL, Elrod CS. Young Adults' perspectives on advance care planning. *Am J Hosp Palliat Care*. 2018;35(4):627-634. doi:10.1177/1049909117727456.
- Pew Research Center. New estimates show U.S. Muslim population continues to grow. <https://www.pewresearch.org/fact-tank/>. Published 2018. Accessed December 11, 2019.
- Pew Research Center. Religion & public life. Muslims in America: immigrants and those born in U.S. see life differently in many ways. <https://www.pewforum.org/>. Published 2018. Accessed December 1, 2019.
- Pew Research Center. Fact tank. Black Muslims account for a fifth of all U.S. Muslims, and about half are converts to Islam. <https://www.pewresearch.org/fact-tank/>. Published 2019. Accessed December 1, 2019.



22. Pew Research Center. The future of world religions: population growth projections, 2010-2050. <https://www.globalreligiousfutures.org/countries>. Published 2015. Accessed December 1, 2019.
23. Prochaska J, Redding C, Evers K. The transtheoretical model and stages of change. In: K Glanz, BK Rimer, K Viswanath, eds. *Health Behavior: Theory, Research, and Practice*. 4th ed. San Francisco, CA: John Wiley & Sons; 2015:97-121.
24. Sudore RL, Heyland DK, Barnes DE, et al. Measuring advance care planning: optimizing the Advance Care Planning Engagement Survey. *J Pain Symptom Manage*. 2017;53(4):669-681.e8. doi:10.1016/j.jpainsymman.2016.10.367.
25. Health-related quality of life. Centers for Disease Control and Prevention website. <https://www.cdc.gov>. Updated October 31, 2018. Accessed March 9, 2020.
26. Rabow MW, McGowan M, Small R, Keyssar R, Rugo HS. Advance care planning in community: an evaluation of a pilot 2-session, nurse-led workshop. *Am J Hosp Palliat Care*. 2019;36(2):143-146. doi:10.1177/1049909118797612.
27. IBM Corp. *IBM SPSS Statistics for Windows, Version 26*. Armonk, NY: IBM Corp; 2017.
28. Eckemoff EH, Sudha S, Wang D. End of life care for older Russian immigrants—perspectives of Russian immigrants and hospice staff. *J Cross Cult Gerontol*. 2018;33(3):229-245. doi:10.1007/s10823-018-9353-9.
29. Grace Yi EH. Does acculturation matter? End-of-life care planning and preference of foreign-born older immigrants in the United States. *Innov Aging*. 2019;3(2):igz012. doi:10.1093/geroni/igz012.
30. Ko E, Lee J. Completion of advance directives among low-income older adults: does race/ethnicity matter? *Am J Hosp Palliat Care*. 2014;31(3):247-253. doi:10.1177/1049909113486170.
31. Rahemi Z, Dunphy LM, Newman D. Preferences regarding and communication about end-of-life care among older Iranian-American adults. *West J Nurs Res*. 2019;41(10):1499-1516. doi:10.1177/0193945919832304.
32. Al-Jahdali H, Baharoon S, Al Sayyari A, Al-Ahmad G. Advance medical directives: a proposed new approach and terminology from an Islamic perspective. *Med Health Care Philos*. 2013;16(2):163-169. doi:10.1007/s11019-012-9382-z.
33. Zafar W, Hafeez H, Jamshed A, Shah MA, Quader A, Yusuf MA. Preferences regarding disclosure of prognosis and end-of-life care: a survey of cancer patients with advanced disease in a lower-middle-income country. *Palliat Med*. 2016;30(7):661-673. doi:10.1177/0269216315625810.
34. The holy Qur'an, translation by A. Yusuf Ali. <https://quranyusufali.com/29/>. Published 2020. Accessed July 30, 2020.
35. Islamic Medical Association of North America (IMANA) Ethics Committee. Islamic medical ethics: the IMANA perspective. *J Islam Med Assoc N Am*. 2005;37(1). doi:10.5915/37-1-5528.
36. Jang Y, Park NS, Chiriboga DA, Radhakrishnan K, Kim MT. The knowing-doing gap in advance directives in Asian Americans: the role of education and acculturation. *Am J Hosp Palliat Care*. 2017;34(9):874-879. doi:10.1177/1049909116668518.
37. Boucher NA, Siddiqui EA, Koenig HG. Supporting Muslim patients during advanced illness. *Perm J*. 2017;21:16-190. doi:10.7812/TPP/16-190.
38. Beaty DD. Approaches to death and dying: a cultural comparison of Turkey and the United States. *Omega (Westport)*. 2015;70(3):301-316. doi:10.1177/0030222815568962.
39. Ward Research, Inc. Healthcare provider and lay person attitudes and perceptions of advance care planning: a focus group report. <http://kokuamau.org/>. Published 2017. Accessed January 20, 2020.

For more than 48 additional continuing education articles related to cultural competence, go to
NursingCenter.com.