Advance care planning associated with demographics but not necessarily preferences: A cross-sectional analysis of NHATS data☆

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Patients and families facing serious illness will frequently need to make difficult decisions about how to balance quality of life with medical treatments as they navigate complex, fragmented care settings. Advance care planning (ACP), which aims to align personal values and preferences with actual care received at the end-of-life, is the process of thinking about, planning for, and documenting guidelines for care in the event of serious illness (Lum, Sudore, & Bekelman, 2015). Written ACPs (wACP), therefore, may include a combination of physician orders for withholding or withdrawing life-sustaining medical interventions, a living will, and power of attorney to designate a surrogate decision maker in the event an individual becomes incapacitated.

Advance care planning is associated with reduced stress for family caregivers, decreased medical interventions at the end-of-life, fewer deaths in the hospital, and lower Medicare costs, which benefits society overall (Lum et al., 2015). Despite this, the rates of ACP engagement remain low, even among older adults who are at risk for decline. In a recent systematic review investigating the proportion of adults in the United States with a wACP such as a living will power of attorney, or other legal document, only 36.7% had any form of wACP (Yadav et al., 2017). Although adults over the age of 65 tend to have higher rates of wACP (45%) overall than younger adults, more than half remain at risk for receiving unwanted care interventions or non-beneficial treatments at the end-of-life (Cardona-Morrell et al., 2016; Yadav et al., 2017). Moreover, racial and ethnic minorities are especially at risk for receiving care incongruent with end-of-life care preferences as they consistently have fewer ACP conversations than non-Hispanic Whites (Clark, Person, Gosline, Gawande, & Block, 2018; Hong, Yi, Johnson, & Adamek, 2018).

The number of racial and ethnic minorities in the United States is growing, therefore, it is essential to understand how diverse populations prefer to engage in ACP. For example, demographic characteristics such as being male, Black, and having poor health literacy have been associated with lower rates of ACP and wACP completion (Hart et al., 2018; Hong et al., 2018). However, poor health status is also associated with ACP engagement across ethnic and racial minorities (Hong et al., 2018). These studies suggest that this may be due more to opportunity than willingness to engage in ACP activities as providing equal opportunity to express end-of-life care preferences increases ACP, wACP rates, and reduces disparities (Clark et al., 2018; Hart et al., 2018).

Nurses, as patient advocates, are well positioned to increase opportunities for all older adults to engage in the process of ACP and affect wACP completion. However, in addition to health disparities, cognitive decline and conflicts within families can also hinder the process (Ke, Huang, O'Connor, & Lee, 2015; You et al., 2015). For example, older adults tend to avoid discussing end-of-life planning with their family members making it difficult for nurses to raise the issue (Ke et al., 2015). Moreover, the majority (60%) of older adults state that they do not want to discuss how long they might live unless their prognosis is poor, and would not want their doctor to discuss life expectancy with their families or friends (Scherrens et al., 2018).

Nevertheless, older adults with chronic illness report higher satisfaction with their physician when ACP is discussed (Lum et al., 2015), and people who identify as Hispanic/Latino may uniquely benefit from end-of-life care conversations as they are less likely to report having had an ACP conversation, and often wait for their provider to raise the issue (Clark et al., 2018). These mixed messages, in combination with other known barriers to ACP such as inadequate knowledge, unrealistic expectations of life-sustaining treatments, and difficulty accepting prognosis continue to place downward pressure on ACP conversations and wACP completion rates across the nation (You et al., 2015).

1. Background

Research using population-level data may make it possible to identify factors such as communication preferences or other items associated with engagement with ACP, thereby providing an evidence-base for individualizing patient care (Hunt, Lee, Harrison, & Smith, 2018). The National Health and Aging Trends Study (NHATS) is a longitudinal, nationally-representative survey of Medicare beneficiaries over age 65 living in the community (including nursing homes and residential care facilities) conducted annually beginning in 2011. The study is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and is conducted by the Johns Hopkins University. The purpose of the NHATS dataset is to identify trends in late-life functioning among older adults, including factors such as residential characteristics, cognition, and self-care activities (Hunt et al., 2018; Kasper & Freedman, 2014).

Combining data-driven approaches with theoretical guidance enhances the clinical relevance of knowledge discovered within large datasets. Decision-making theory is useful in guiding providers in evaluating and understanding an individual's readiness to engage in discussions about serious illness goals for care, thereby positively affecting their rates of completion (Fried et al., 2016; Lum et al., 2015). The stages of change theory, initially developed to promote health behavior change such as smoking cessation, and later in the context of ACP, assumes that people need to come to terms with the need to plan for the end-of-life, which is a process that takes time (Fried et al., 2016; Lum et al., 2015; Prochaska & Velicer, 1997). Therefore, ACP is a multistep process that individuals progress through in various degrees of readiness before completing a wACP.

The stages of change model include five steps towards health behavior change: pre-contemplation, contemplation, preparation, action, and maintenance (Table 1) (Prochaska & Velicer, 1997). The stages of change theory, therefore, helps promote a better understanding of patient and family approaches to decision-making and supports clinicians in guiding person-centered care discussions (Sullivan, in press; Fried et al., 2016; Lum et al., 2015). Guided by decision-making theory for the selection of variables (Table 1), the purpose of this study is to use a nationally representative dataset of older adults living in the community to understand whether individuals with a wACP have different characteristics, outcomes, or care preferences than those who do not. Having this knowledge will provide an evidence-base for identifying approaches to engage individuals in ACP discussions and for the future development of personalized approaches to care.

2. Methods

2.1. Study design

This is a cross-sectional secondary analysis of data from the NHATS study (Hunt et al., 2018; Kasper & Freedman, 2014). A multi-disciplinary team of researchers, including demographers, geriatricians, epidemiologists, health services researchers, economists, and gerontologists designed the NHATS content around a conceptual framework that distinguishes between physical and cognitive capacity and the environment (National Health and Aging Trends Study (NHATS), 2019). The NHATS study provides a large database for longitudinally characterizing trends in late life functioning in adults over age 65 and over residing in the coterminous United States. National Health and Aging Trends Study data were obtained by interviewing individuals (directly, or through a proxy) according to the NHATS protocol (Kasper & Freedman, 2014). The initial survey (Round 1, 2011) included 12,427 individuals (with replenishment in 2015). In 2012 only, a supplemental ACP questionnaire was administered to a subset of NHATS participants. The most recent data (Round 7) was released in 2017. Public and sensitive data were downloaded from the NHATS website after access to the sensitive data was granted. Each data point was treated as a single individual. IBM SPSS Statistics version 23 software was used for all analyses.

2.1.1. Study sample

The total NHATS study population (n = 12,427) and a subsample of participants who were asked about end-of-life discussions and wACP (n = 1993) in Round 2 (2012) are the unit of analysis for the study. Individuals who answered yes or no to the question about whether they had discussed their end-of-life preferences with anyone ("EOL sample" n = 1993) is used in its entirety. A sample of 160 people is needed to detect a wACP prevalence of 40% (± 10%) at β = 0.2 (power = 80%) and α = 0.01 (Hulley, Cummings, Browner, Grady, & Newman, 2013). Sample characteristics include age, sex, race, ethnicity, and place of residence (geographical region and metropolitan/non-metropolitan), end-of-life discussion occurrence, end-of-life preferences, and wACP. Individuals who subsequently died are identified according to data from Rounds 3–7.

2.1.2. Demographic variables

Demographic information was extracted directly from NHATS and sensitive data files including age, sex, race, ethnicity, geographic area of residence, and metro/non-metro status of residence. NHATS represents ethnicity as a stand-alone variable according to whether an individual self-identified as Hispanic/Latino. The NHATS categories for metro/non-metro available in the non-restricted data files are based on Rural-Urban Continuum Codes (RUCC), with metro defined as RUCC 1–3 and non-metro as RUCC 4–9 (United States Department of Agriculture Economic Research Service (USDA), 2018, October 29).

2.1.3. End-of-life discussion and preferences

Designation of whether an individual said they had ever discussed their end-of-life preferences with anyone was taken directly from the

Table 1
The stages of change within the context of advance care planning[a].
Adapted from Prochaska and Velicer (1997).

Stages of change	Behavior	NHATS variables
Pre-contemplation	Unaware of ACP, not prepared to consider completing a wACP[b], possible avoidance of the issue	Demographics (age, sex, race, and ethnicity), values, exposure to ACP, "Make decisions with/or advice from…together…or leave up to …?"
Contemplation	Ambivalence, weighing of options	Culture and environment (metro/non-metro), health status, access, literacy, "Would you want treatment if…?"
Preparation	Considering action and possibly open to learning more about ACP and wACP	Discussions about goals for care with others and explore options for wACP, "Have you ever talked to anyone about…?"
Action	Definitive action towards wACP but remains tentative, not ready to fully commit	Discussion and/or wACP, "Do you have…?"
Maintenance	Working to maintain commitment to ACP, may revisit previous stages	wACP with continued discussion and revisions (not available in NHATS dataset).

[a] ACP = Advance Care Planning.
[b] wACP = Written Advance Care Plan.

Table 2
Sample characteristics (*n* = 1993).

Characteristics	M (SD)	*n*	%
Age	78.6 (7.6)		
Male		851	42.7
"EOL Talk" Yes		1156	58.0
wACP Yes[a]		1171	60.1
Race[b]			
White		1449	73.3
African American		449	22.7*
Native American		13	0.7[§]
Asian		31	1.6*
All others		34	1.7
Ethnicity[c]			
Hispanic/Latino Yes		117	5.9

[a] Missing data *n* = 46 percentages calculated on *n* = 1947.
[b] Missing data *n* = 17 percentages calculated on *n* = 1976.
[c] Missing data *n* = 14 percentages calculated on *n* = 1979.
* *p* < 0.001 compared to White.
[§] *p* = 0.05 compared to White.

associated NHATS variable. End-of-life preferences were characterized by responses to the NHATS questions regarding whether the individual would want to withhold or withdraw life-sustaining treatments if: 1) they were in constant pain, and 2) if they could not walk or talk.

2.1.4. wACP variables

A dichotomous yes/no variable for having any sort of wACP was created from two NHATS variables regarding whether an individual had a power of attorney (POA) and whether an individual had a living will (LW). The dichotomous wACP variable was set to "no" if an individual had neither a POA nor a LW, and set to "yes" if an individual had either a POA, a LW, or both POA and LW.

2.1.5. Death-related variables

Individuals with non-missing age at death during any of Rounds 3–7 were denoted as having died after Round 2. Age at death and place of death were extracted from the dataset corresponding to the Round in which an individual had died. Values for place of death were coded as denoted in NHATS for home, hospital, nursing home, and hospice facility while all others were coded as other.

2.1.6. Decision-making involvement of others (total NHATS sample)

The level of desired involvement of others in health care decision-making for individuals is characterized by two NHATS variables: 1) involvement of doctor, and 2) involvement of family members. Involvement was described by one of four levels: 1) making decisions alone without others, 2) getting advice from others and then deciding, 3) making decisions jointly with others, and 4) having others make decisions for them. Because responses to these decision making involvement questions were "missing" for the "EOL sample" decision making involvement was analyzed in the overall NHATS population by race category. Race category was selected as the variable of interest to determine if there were differences in wACP rates by race and if the desired level of involvement of family members and providers in decision-making differs by race/ethnic group. Understanding communication preferences in this way may provide an entrée for providers to raise the issue of decision-making preferences, and therefore ACP, as routine standard of practice, rather than in the context of declining health status (Hong et al., 2018).

2.2. Study analyses

2.2.1. Sample characteristics

The sample is described by means (s.d.) for continuous variables and frequencies for categorical variables.

2.2.2. Associations among variables

For age, means were compared between groups subdivided according to categorical variables. For all other variables, contingency tables (created using the SPSS crosstabs function) were used to visualize associations between patient characteristics and: 1) end-of-life discussions & preferences, 2) wACP possession (yes/no), and 3) death-related variables (i.e. place and age of death). Contingency tables were also used to visualize associations between end-of-life preferences, wACP possession, and death-related preferences. Layering, risk estimate and column percentage difference, features of the SPSS crosstabs function, were used to identify significant (*p* < 0.05) associations. Where applicable, odds ratios (OR) and risk ratios (RR) were recorded to quantify differences. For contingency tables in which SPSS did not identify differences, general trends in numbers were used to identify potential anomalies warranting further investigation. Chi-square was used to determine differences between sample distributions.

3. Results

3.1.1. Sample demographics

Study demographics are available in Table 2. The sample averaged 78.4 years old (s.d. = 7.6, range 66–100) at the time of the Round 2 ACP interview (year 2012), with 42.7% (*n* = 851) being male and (57.3%, *n* = 1142 female). Racially, the sample self-identified as being primarily White (72.7%) with 22.5% identifying as African American, 0.7% Native American, and 1.6% Asian, and all other races combined 1.7% (primary race was used for individuals who identified as more than one race because the response called for "check all that apply"). Additionally, 5.6% of the sample identified as Hispanic/Latino. Distribution of residences across the nine geographic regions utilized by NHATS for the "EOL sample" (*n* = 1993) mirrored that of the overall NHATS Round 2 sample (*N* = 7075); 82% of the residences were identified as metro, and 18% as non-metro.

Sample EOL Discussion and ACP Possession Characteristics.

Among the "EOL sample" 58.0% said they had discussed end-of-life preferences with someone, and 60.1% reported having a wACP. Among those who responded "yes" they had discussed their end-of-life preferences with someone, 79.6% reported having wACP; that is, 20.4% of those who indicated they had discussed end-of-life preferences with someone did not complete a wACP. The rate of wACP completion was lower for those who responded "no" to having discussed end-of-life preferences with someone, yielding OR [95% C.I.] = 7.8 [6.4–9.7] for having wACP among those who did vs. did not have end-of-life discussions. This finding suggests that goals of care discussions are strongly associated with higher rates of wACP completion.

3.2. Sample death-related characteristics

Just over a fifth (23.1%, *n* = 460) of the" EOL sample" died over the next five years, with average age of death = 85.7 years (sd = 7.2), and 45% male. Age of death was older for women (87, sd = 7.3) compared to men (84, sd = 7.5, *t* = 4.138, *p* < 0.001). Most frequently, individuals died at home (36.7%), with 28.2% dying in hospitals, 18.8% dying in skilled nursing facilities, 11.6% dying in hospice facilities, and 4.7% dying in other locations. End-of-life discussions had been reported by 59.3% (*n* = 273) of those who died, 70% had a wACP (*n* = 313 of the 447 with non-missing wACP data).

3.3. wACP possession – demographic associations

Individuals without wACPs were 4 years younger (age = 76 years, sd = 6.9) on average than those with wACPs (age = 80 years, sd = 7.7, *t* = −9.5, p < 0.001). Within the" EOL sample," 56.8% (*n* = 476) of men and 62.7% (*n* = 1109) of women reported having wACP. Among
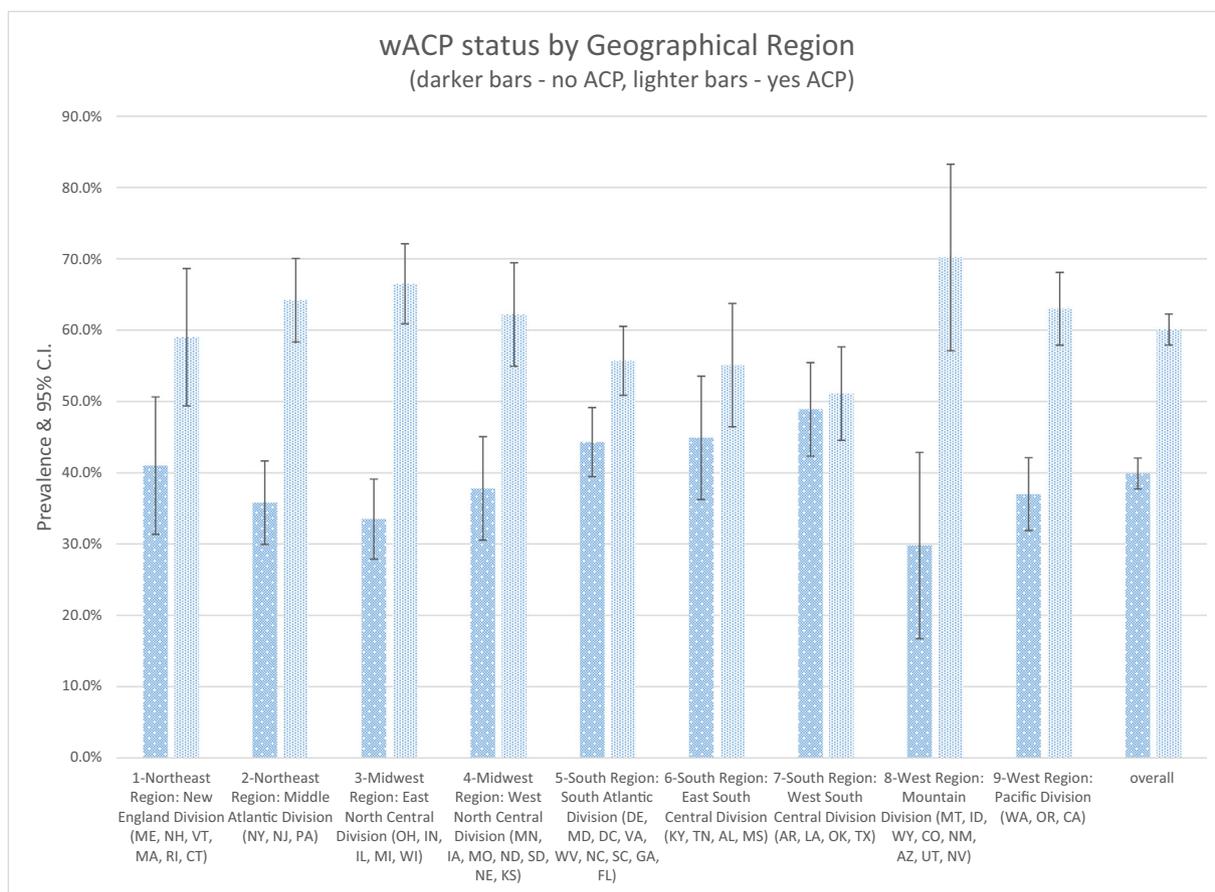
Fig. 1..

the different races, 67.6% of Whites, 40.5% of African Americans, 46.2% of Native Americans, and 36.7% of Asians reported having wACPs. Thus, among this study's sample, African Americans (Z = 10.16, p < 0.001), Native Americans (Z = 1.64, *p* = 0.05), and Asians (Z = 3.57, p < 0.001) all had lower rates of wACP compared to Whites. Among those living in metropolitan areas and non-metropolitan areas, 59.8% and 61.6%, respectively, reported having wACPs; this metro/non-metro difference was not statistically significant at *p* < 0.05 (Fig. 1).

3.4. wACP possession – EOL preference associations

Two NHATS items explored end-of-life preferences, regarding whether an individual would hypothetically want to withhold or withdraw all treatments if they were: 1) in constant pain, or 2) could not walk or talk. These variables were chosen to explore the use of the questions to identify individuals who are potentially contemplating a health behavior change (i.e. completing a wACP) (Table 1). Among the "EOL sample" as a whole, 71% (*n* = 1119/1583) reported wanting to withhold or withdraw all treatment if in constant pain and 81% (*n* = 1307/1614) reported wanting to withhold or withdraw all treatments if unable to walk or talk.

3.4.1. Pain incongruence

Among those who wanted to withhold or withdraw all treatment if in constant pain (n = 1119), 24.6% (*n* = 390) reported being without a wACP. In terms of race and ethnicity, 29.1% of Whites, 57.3% of African Americans, 40.0% of Native Americans, 37.5% of Asians and 60% of Hispanic/Latinos who said they would withhold or withdraw all treatments if in constant pain, also did not have a wACP.

3.4.2. Walk or talk incongruence

Among those who wanted to withhold or withdraw all treatment if they were unable to walk or talk (*n* = 1614), 28.6% (*n* = 461) were without a wACP. In terms of race and ethnicity, 30.2% of Whites, 55.0% of African Americans, 50.0% of Native Americans, 50.0% of Asians and 62.1% of Hispanic/Latinos who said they would withhold or withdraw all treatments if unable to walk or talk, also did not have a wACP.

3.5. Decision-making involvement of others (total NHATS sample)

The results above indicate apparent incongruences between wanting to withhold or withdraw all treatments yet being without a wACP. In consideration of such incongruences, the way in which individuals involve others in decisions about their health care was examined to determine if this might offer additional insight into their readiness for health behavior change (i.e. completing an wACP) (Table 1). However, such insights were inferred from the overall NHATS sample (*N* = 7075), as these decision-making involvement data were not directly available for the "EOL sample."

As seen in Table 3, there are differences between racial and ethnic groups in terms of the extent to which an individual desires to involve their physician and/or families in end-of-life decision making. Across groups, the majority of individuals prefer to either get advice or make decisions together with their physicians and family members. However, there are some interesting differences between racial groups in terms of those who prefer to make decisions alone versus leaving decisions them up to their physician. For example, only 7.7% of Asians and 8.3% of Whites prefer to make decisions independent of their physicians, while 10.9% of African Americans, 12.3% of Native Americans, and 13% of those who identify as Hispanic/Latino prefer to make decisions about end-of-life care options without medical advice. Likewise, Whites

Table 3

National Health Aging and Trends (NHATS) engagement in healthcare preferences by race and location metro/non-metro).

Characteristics	NHATS variable name (*n*)	NHATS engagement in healthcare[a] (all Round2 participants with valid data for these variables)				p-Value[c]
		Make decisions without much advice from them[b] (%)	Get their advice and then make decisions[b] (%)	Make decisions together[b] (%)	Leave decisions up to them[b] (%)	
Physician	eh2advicedoc					
Total	6107	8.9	37.5	36.6	17	–
White	537	8.3	39.3	36.6	15.8	Reference
African American	1588	10.9	32.4	36.6	20.2	< 0.001
Native American	1982	12.3	31.6	36.8	19.3	< 0.001
Asian	2000	7.7	30.8	38.5	23.1	< 0.001
Hispanic/Latino	115	13	40.0	32.2	14.8	Reference
Not-Hispanic/Latino	1910	8.7	37.4	36.9	17.0	< 0.001
Metro	1645	8.3	38.2	36.9	16.6	Reference
Non-Metro	394	11.7	34.3	35.3	18.8	< 0.001
Family	eh2advicefam					
Total	6123	37.7	27.6	29.5	5.2	–
White	539	38.2	28.6	28.4	4.9	Reference
African American	1592	35.4	25.7	32.1	6.9	< 0.001
Native American	1987	45.6	17.5	31.6	5.3	< 0.001
Asian	2005	33.3	17.9	46.2	2.6	< 0.001
Hispanic/Latino	116	28.4	29.3	34.5	7.8	Reference
Not Hispanic/Latino	1913	38.2	27.5	29.3	5.0	< 0.001
Metro	1648	38.0	27.6	29.2	5.2	Reference
Non-Metro	396	36.4	27.5	31.1	5.1	< 0.001

[a] People today are faced with many decisions about their healthcare—for example whether to start or change a medicine. We want to know how you prefer to have doctors and family or friends help with decisions."

[b] "Thinking about your doctor/family first, do you prefer to make decisions: without much advice from them, get advice and then make decisions, make decisions together, or leave decisions up to them?"

[c] p-Value for difference of the given distribution relative to reference group, per chi-squared test.

(15.8%) have the lowest overall rates of wanting to rely on their physician exclusively while Asians have the highest rates (23.1%).

Across all racial and ethnic groups, the desire to leave decisions exclusively up to family members (range 2.6–7.8%) was far less than those who preferred to leave decisions up to their physicians (range 14.8–23.1%). Native Americans most frequently stated they would want to make decisions without much advice from their families (45.6%), while Hispanic/Latinos (28.4%) were the least likely to want to make decisions without advice. However, those who identified as Hispanic/Latino also had the highest rates of wanting to leave decisions up to their family members (7.8%), while many fewer Asians (2.6%) wished to defer to their family members. These findings suggest that there are distinct preference patterns for family involvement in decision making that may be useful in identifying approaches for engaging in ACP discussions that are concordant with the individual's preferences (i.e. asking "To what extent would you like to involve your physician or family members in making end-of-life decisions?").

4. Discussion

This study used decision-making theory to characterize the attributes, outcomes, and care preferences of older adults living in the community based on whether or not they had created a wACP using the nationally representative NHATS dataset. The data revealed interesting insights about ACP in older adults residing in the community. Importantly, the overall rates of wACP among NHATS participants are higher (60.1%) than reported in prior studies (45%) (Yadav et al., 2017). This may be because some NHATS participants lived in a nursing home or residential care facility or were enrolled in a palliative care program, and are therefore more likely to have been exposed to formal ACP processes. In addition, goals of care discussions are strongly associated with wACP completion rates (79.6%) among older adults participating in the NHATS study. This is true for both Whites (67.3%) and racial minorities living in the community (range 36.7–47.2%) compared to the literature (< 30% for ethnic minority groups) (Hong

et al., 2018). Given that end-of-life care preferences are also influenced by local practice patterns and clinician bias (Barnato, 2017) the findings of this study suggest that providing opportunities to discuss end-of-life preferences may promote ACP among diverse older adults living in the community. This finding is consistent with the work of Hart et al. (2018).

Using large datasets to discover patterns at the population-level may therefore contribute to the development of standardized, evidence-based decision support tools to prompt person-centered care interventions, including ACP discussions (Hewner, Sullivan, & Yu, 2018; Klingman & Boyce, 2018; Sullivan, Hewner, Chandola, & Westra, 2019; Sullivan, in press). In addition, as found in this study, it may be important in the clinical setting to consider the patient's desired approaches to having discussions as a way to improve the rates of wACP. Future research should also explore ways to gather information about opportunities to complete wACP (Hart et al., 2018). Moreover, it is important to continue investigating alternative approaches to ACP that are grounded in individual value systems such as desire to engage others in goals of care conversations.

This study also revealed an incongruence between expressed goals for care and actual wACP completion rates among many NHATS respondents. Although respondents indicated that they would want to withhold or withdraw all treatment if they were either, in intractable pain (24.6%) or could not walk or talk (28.6%), these same respondents had not completed a wACP. It is possible that these individuals are in the pre-contemplation (unaware of ACP or not prepared to change) or the contemplation stage (ambivalence) of ACP and identifying this group may yield individuals who may be targeted to respond positively to goals of care discussions (Sullivan, in press) (Table 1).

Moreover, African Americans, Native Americans, and those who identify as Hispanic/Latino preferred to either make decisions alone without guidance from their physician, or leave decisions up to them at greater rates that Whites (Table 3). Asians, on the other hand were significantly more likely to want decisions to be made for them by their physicians (23.1%) than to make them alone (7.7%). It is possible that

certain minority groups have a mistrust of the healthcare system, however, more minorities in this study preferred to leave decisions up to their physicians than Whites (except for those who identify as Hispanic/Latino), which is contrary to this assumption. This replicates the findings from a recent systematic review, which found that mistrust was a barrier among ethnic minority groups only for participants who reported their race to be Black (Hong et al., 2018).

However, when asked about making decisions alone compared to leaving decision-making up to their family, respondents across all groups strongly preferred to make decisions alone. These findings, which are consistent with prior research (Chiu, Feuz, McMahan, Miao, & Sudore, 2016), suggest that simply asking about preferences for care and degree to which one would want their physician or family member involved in decision making not only promotes dignity and autonomy, but it helps providers understand preferences for engaging in ACP and may also improve patient satisfaction.

This study is not without limitations. First, it is important to recognize that race does not imply ethnicity or background, therefore these results should be interpreted with caution, and the small sample size in some race categories may influence inferences. Moreover, it was necessary to extrapolate some data from the population because questions about decision control preferences were not available in the sample of individuals interviewed about end-of-life in 2012. Future studies should include asking older adults about their preferences about how much they want others involved, as this is an emerging area of research (Chiu et al., 2016).

Second, the "Engagement in Health" NHATS questions ask if a person would want physician or family involvement in medical decision making by using a hypothetical example of medication change decisions (Table 3). It is possible that this question does not represent end-of-life issues well. However, this question is presented in a series about decision preferences and it is possible that it was interpreted to be related to end-of-life decisions. Moreover, participants were asked to speculate on hypothetical scenarios of pain and incapacity, and although these vignettes may help to get a better understanding of preferences, perspectives may change over time or when faced with serious illness (Auriemma et al., 2014).

Third, a number of people indicated that they did *not* have an ACP discussion, yet they had a wACP. This may be to their disadvantage because ACP is a process that takes time and wACP are not necessarily effective alone. Rather, end-of-life decision-making requires context (which changes over time), discussion, and integration into the plan of care (Auriemma et al., 2014; Lum et al., 2015). It is possible that the patient or their surrogate made these decisions independently; however, this remains unknown based on the variables included in the NHATS study. Moreover, there were some interesting differences in the metro/non-metro location data, which should be explored in future research. Finally, some variables, which may also influence wACP were not included in this study (e.g. socio-economic status and education).

5. Conclusion

An analysis of the National Health and Aging Trends Study has reveals novel insights into the ACP and wACP characteristics, outcomes, and preferences of older adults who reside in the community. This study identifies inconsistencies between personal preferences for care at the end-of-life, wACP completion rates, and potential racial and ethnic differences about the extent to which older adults want others involved in their decision-making. Acknowledging and addressing these differences may help to identify individuals who are potentially ready to engage in health behavior change (i.e. ACP), may provide earlier access to ACP discussions, while respecting their choices about the involvement of others. For example, as shown in Table 1, when evaluating an individual's readiness to engage in ACP, if a person is assessed as being in the pre-contemplation stage, it may be helpful to first inquire about their desired level of physician or family involvement in decision

making before raising the issue of ACP.

To date, much research has focused on identifying characteristics of individuals as potential indicators for appropriately timing end-of-life discussions, such as demographics or indices of mortality risk. Guided by behavior change theory, this study presents alternative approaches for screening a person's readiness to engage in ACP, in addition to recommending that preferences for physician and family involvement be elevated as an essential front-line assessment question. This is especially important when it is necessary to identify healthcare surrogates that are congruent with the preferences of older adults (Chiu et al., 2016). Lastly, this study demonstrates how nurses can analyze big datasets to develop patient-centered approaches to care of individuals at the end-of-life and develop evidence-based decision support tools (Hewner, Sullivan & Yu, 2018; Klingman & Boyce, 2018;Sullivan, et al, 2019). The literature contains many references to the benefits of mining big data, although end-of-life care has yet to reap full benefits of such approaches.

Acknowledgement

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