Barriers to Completing Advance Care Planning: Insights From the Wausau Free Clinic

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ABSTRACT

Background: Advance care planning (ACP) encourages individuals to express their health care wishes should they become incapacitated and to use an advance directive to designate an individual to make health care decisions on their behalf.

Methods: A survey on ACP was administered at the Wausau Free Clinic in Wausau, Wisconsin in English or Spanish to participants 18 or older from February to May 2023.

Results: Of 46 respondents, 80% had not heard of ACP. One in 10 said a physician had had a conversation with them about ACP. Health care access and lack of education were the biggest challenges to ACP.

Discussion: Most individuals who utilize the clinic were unaware of ACP. Wisconsin is not a "next of kin" state, which increases the importance of ACP completion.

BACKGROUND

Advance care planning (ACP) is the process of having important conversations to indicate one's medical wishes in anticipation of future health care decisions. The goal of an ACP session is to facilitate discussions between clinicians, patients, and their medical decision-maker surrounding the patient's desires and values related to end-of-life care.[1] An advance directive includes a living will and a durable power of attorney for health care. It is a physical, legal document that is used to inform a health care provider what treatments a patient would like if they are unable to make decisions and identifies an individual to make those decisions. An advance directive can be completed if a person is 18 years or older and in sound mind.[1] In some states, if a person has not completed an advance directive, their next of kin can make decisions for them if they are incapacitated. However, Wisconsin is not a "next-of-kin" state, meaning a court-appointed guardian makes decisions for a person if they do not have an advance directive.[2]

Approximately 1 in 3 adults in the United States have completed any type of advance directive.[3] However, a study of Hispanic and non-Hispanic White patients found that participants who identified as Hispanic were less than half as likely to have an advance directive in their medical record as their non-Hispanic White counterparts.[4] Moreover, an older study conducted in Colorado reported Hispanic patients had significantly lower rates of ACP conversations (29%) than White patients (54%).[5] In a previous study of a statewide random-digital dial telephone survey of adults 18 years or older, participants who identified as Hispanic were less likely than non-Hispanic White participants to have named a health care agent or have conversations about their end-of-life wishes with family or friends.[6]

To better understand the barriers and ethnic differences with ACP and advance directive completion, we conducted a survey at the Wausau Free Clinic, located in Wausau, Wisconsin, where the population is over 74% Hispanic and nearly 80% minority.

METHODS

An initial literature review determined barriers faced by people who are Hispanic when completing ACP and guided the creation of a 10-question survey (Appendices A and B), with questions derived from a previous survey.[7] Content of the surveys included basic demographics, respondent's general knowledge of ACP and health care power of attorney, previous conversation about

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Table 1. Demographics of Survey Respondents

Category	No. of Respondents (n)	Proportion of Total (%)
Ethnicity, proportion		
Hispanic or Latino	34	74
Non-Hispanic or Latino	11	24
Did not indicate	1	2
Age, proportion (%)		
18–24	5	11
25–34	10	22
35–44	13	28
45–54	9	20
55–64	7	15
65–74	2	4

Table 2. Barriers to Completing Advance Care Planning

Barrier[a]	No. of Respondents (n)	Proportion of Total (%)
Health care access	21	34
Lack of education	17	27
Fear	6	10
Cultural beliefs	3	5
Spiritual beliefs	4	6
Other challenges[b]	11	18

[a]This question was asked in "select all" format. Hence, there are more answers than the total number of survey respondents.

[b]Of the respondents who selected "other challenges," 1 respondent noted "reading," 1 noted "family," 1 noted "transportation," 1 noted "work," and 2 noted "time" as barriers, while 5 respondents did not comment in the provided box as to what "other challenge" they experienced regarding advance care planning completion.

ACP with physicians, desires to learn more about ACP, preferred method of information delivery, and barriers to completing ACP. To create a culturally relevant survey, the research team worked with a Spanish interpreter to review, edit, and translate the survey to match an eighth grade reading level.

After a nurse obtained patients' vital signs, an anonymous survey was administered via Qualtrics to each willing patient 18 years or older who presented at the clinic on Thursday afternoons from February to May 2023. An informational letter was included at the top of the survey and completion was voluntary. The patient completed the survey directly in English or Spanish or verbally answered the questions as read by the interpreter, depending on the respondent's literacy.

After survey completion, data were analyzed qualitatively for common themes and quantitatively with descriptive statistics using an Excel spreadsheet. The Medical College of Wisconsin Institutional Review Board deemed this project quality improvement.

RESULTS

Of the 46 respondents, 74% were Hispanic or Latino. Respondents were aged 35 to 44 years (28%), followed by 25 to 34 years (22%), 45 to 54 years (20%), 55 to 64 years (15%), 18 to 24 years (11%), and 65 to 74 years (4%) (Table 1). Eighty-five percent of the respondents had not heard of ACP; however, 65% responded "yes" to learning about ACP, 24% responded "maybe," and 15% reported they had no desire to learn about ACP. Although 70% reported they have someone in the US to make health care decisions for them, only 17% had a legal document designating that individual. Most of the respondents (72%) did not have a health care power of attorney.

Only 1 in 10 participants reported a physician has had a conversation with them about ACP. Regarding ACP education, 52% of respondents preferred 1:1 learning, 26% preferred small group learning, 7% preferred large group learning, and 15% were not interested in an ACP education session. Barriers to completing ACP included health care access (34% of total responses), followed by lack of education (27%), fear (10%), cultural beliefs (5%), spiritual beliefs (6%), and other challenges (18%). Free responses were used to describe "other challenges" and included "reading" (1 response), "family" (1 response), "transportation" (1 response), "work" (1 response), and "time" (2 responses). Five respondents did not comment in the provided response area (Table 2).

DISCUSSION

Crooks and Trotter[8] described no statistical difference in the number of informal conversations surrounding end-of-life care throughout various ethnicities, but there remains a large discrepancy in the percentage of people who go on to complete an advance directive. Our surveys replicate these findings within the Hispanic population: most respondents stated they have someone to make medical decisions for them, yet few have the supporting legal document. The lack of understanding of ACP and low completion of advance directives within the study population have significant implications within Wisconsin, which is not a next-of-kin state.[2] This process can cause distress among family members by delaying care and appointing an individual unknown to the family to make life-altering decisions for them. This delay also yields a lower quality of care for the patient.

According to our findings, noted barriers to ACP completion include lack of education, fear, differing belief systems, and health care access. Discrepancies in the language used within the documents is also a well-documented barrier to completion, which may be correlated with lack of education about ACP. Puerto and colleagues[9] identified confusion around the language used in ACP documents and differing levels of knowledge depending on the respondent's country of origin. In Spanish, there are multiple words used for "advance care planning," which creates confusion around the document's intent. Furthermore, some countries do not have ACP, making it an unfamiliar topic for immigrants. Addressing language barriers through easy-to-understand ACP materials, including using resources no higher than an eighth grade reading level, is necessary to increase advance directive

completion. Most respondents at our clinic prefer 1:1 learning, and we believe easy-to-understand ACP pamphlets meet this need. Additionally, integrating ACP conversations as an additional "vital sign" ensures the health care team has a conversation with every individual about an advance directive, even if it is short.

A smaller percentage of total respondents named fear as a barrier to ACP completion, although this was an open question without description of the specific fear. Puerto et al[9] reported that religious beliefs also may contribute to lack of ACP completion due to a belief that discussing death may "interfere with God's plan." A similar number of participants noted their cultural beliefs surrounding decision-making as a barrier. Family structure and the decision-making process in traditional Hispanic culture differs from American culture. Hispanic culture values the immediate family making shared decisions, rather than 1 or 2 appointed proxies.[8] This structure creates difficulty within Wisconsin and can lead to medical preferences not being followed. Although fear, spiritual beliefs, and cultural beliefs may be connected, it remains unclear from our survey how fear and belief systems interrelate to affect ACP completion. Nevertheless, it is important for health care providers to explain advance directives to their patients sensitively.

Survey results identifying that 1 in 10 participants have had a conversation with a physician about ACP highlights the importance of ACP education in the health care setting. Our clinic curbs financial and health literacy barriers to health care, and other free clinics could become systems to address the mismatch between informal ACP and completing advance directives. In Wisconsin there are more than 90 clinics affiliated with the Wisconsin Association of Free and Charitable Clinics, which may be an initial place to increase ACP within the state.[10] Regardless of the free clinic status, however, our findings are applicable to all health care settings given the gravity of Wisconsin not being a next-of-kin state.

Another method to reduce barriers to ACP completion includes bringing ACP conversations into non-health care settings, such as churches, community spaces, or workplaces. Overall, there is a great need for increased ACP education, cultural competency, and expanded communication to ensure peoples' wishes are honored—all in a timely fashion and without having to appoint a legal guardian from the Wisconsin court system.

Limitations

This study's sample size is small due to study time restraints, which may provide a less representative sample of the study population. Our survey specifically asked participants if physicians have had a conversation with them about ACP, although we could have asked broadly about health care providers, such as advanced practice providers. Moreover, the relatively young age of our survey respondents may have been a confounding factor. Additionally, results are taken from 1 health care partner providing services to people who are uninsured, so results may differ at other health care facilities. Lastly, although interpreters were present during survey administration, health literacy barriers may have affected participants' understanding of the survey.

Funding/Support: None declared.

Financial Disclosures: None declared.

Acknowledgements: The authors would like to thank Paula Vogt, RN, and Leslie Thiele for their ACP expertise and assistance with drafting the questionnaire and Francisco Guerrero, a Health Coverage Navigator and Spanish Interpreter for assisting in the creation of the survey, as well as the other Spanish interpreters who helped administer the survey at the WFC. They would also like to thank Kim Shibilski for helping with the administration of the project into clinic workflow.

Appendices: Available at www.wmjonline.org.

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