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Wellness in Sickness and Health (The W.I.S.H. Project): Advance Care Planning Preferences and Experiences Among Elderly Latino Patients

Lauren Y Maldonado ^a, Ruth B Goodson^a, Matthew C Mulroy^a, Emily M Johnson ^{a,b}, Jo M Reilly^{a,b}, and Diana C Homeier^{a,c}

^aKeck School of Medicine of the University of Southern California, Los Angeles, California, USA; ^bDepartment of Family Medicine, LAC+USC Medical Center, Los Angeles, California, USA; ^cDepartment of Family Medicine and Geriatrics Clinic, LAC+USC Medical Center, Los Angeles, California, USA

ABSTRACT

Objective: To assess advance care planning (ACP) preferences, experiences, and comfort in discussing end-of-life (EOL) care among elderly Latinos.

Methods: Patients aged 60 and older from the Los Angeles County and University of Southern California (LAC+USC) Medical Center Geriatrics Clinic ($n = 41$) participated in this intervention. Trained staff conducted ACP counseling with participants in their preferred language, which included: (a) pre-counseling survey about demographics and EOL care attitudes, (b) discussion of ACP and optional completion of an advance directive (AD), and (c) post-session survey.

Results: Patients were primarily Spanish speaking with an average of 2.7 chronic medical conditions. Most had not previously documented (95%) or discussed (76%) EOL wishes. Most were unaware they had control over their EOL treatment (61%), but valued learning about EOL options (83%). Post-counseling, 85% reported comfort discussing EOL goals compared to 66% pre-session, and 88% elected to complete an AD. Nearly half of patients reported a desire to discuss EOL wishes sooner.

Conclusions: Elderly Latino patients are interested in ACP, given individualized, culturally competent counseling in their preferred language.

Clinical Implications: Patients should be offered the opportunity to discuss and document EOL wishes at all primary care appointments, regardless of health status. Counseling should be completed in the patient's preferred language, using culturally competent materials, and with family members present if this is the patient's preference. Cultural-competency training for providers could enhance the impact of EOL discussions and improve ACP completion rates for Latino patients.

KEYWORDS

Advance health care directive; Hispanic/Latino; elderly; palliative care; medicine

Introduction

Advance care planning (ACP) provides numerous benefits to patients, families, and the healthcare system. ACP aligns treatment with patients' end-of-life (EOL) wishes by preserving autonomy in medical decision-making (Detering, Hancock, Reade, & Silvester, 2010; Ditto et al., 2001). Relieving family burden, achieving a sense of control, avoiding pain, and strengthening relationships with family are additional patient-perceived benefits of ACP (Detering et al., 2010; Singer, Martin, & Kelner, 1999). Notably, the prevention of unwanted treatment and associated reduction of unnecessary medical cost in an era of unprecedented healthcare expenditures offer considerable economic benefits.

Despite these advantages, less than 30% of Americans participate in ACP and fewer than 20% have documented EOL wishes in an advance directive (AD) (Milnes et al., 2017; Rao, Anderson, Lin, & Laux, 2014); however, 70% of patients express concerns about their EOL care (Rao et al., 2014; Sharp, Moran, Kuhn, & Barclay, 2013). Setting and socio-demographic context may influence disparities in AD completion rates. One study reported that 70% of decedent, non-Hispanic Medicare beneficiaries had either a durable power of attorney or a living will at their time of death, illustrating that factors such as race/ethnicity, age, and insurance status may contribute to disparities between population subsets (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Importantly, racial/ethnic minorities are historically

CONTACT Lauren Y Maldonado  lymaldon@usc.edu

Lauren Y. Maldonado and Ruth B. Goodson contributed equally to this work.

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less likely to participate in EOL discussions or document care goals. Though the literature on ACP utilization among racial/ethnic minorities is sparse, studies consistently reveal that non-Latino white patients are significantly more knowledgeable about and more likely to complete ADs than any other racial/ethnic group (Kwak & Haley, 2005).

While Latino patients comprise the largest minority group in the U.S. health care system, the literature exploring their EOL care preferences in a non-acute setting is limited (U.S. Census Bureau, 2011; Zaide et al., 2013). Most existing studies focus on EOL wishes among Latino adults diagnosed with advanced, terminal cancer rather than in the non-acute, outpatient setting (Carrion, Nedjat-Haiem, Estapé, & Franco-Estrada, 2017; Carrion, Nedjat-Haiem, Macip-Billbe, & Black, 2017; Carrion, Nedjat-Haiem, & Marquez, 2013). This lack of information places the majority of elderly Latino patients at greater risk of receiving care inconsistent with their wishes (Kelley, Wenger, & Sarkisian, 2010). As the U.S. Latino population is estimated to increase from 55 million currently to 119 million by 2060, the number of patients receiving inappropriate EOL care will likely continue to grow (Colby and Ortman, 2015). Preference for family-centered decision-making, low health literacy, language and cultural barriers with providers are additional challenges Latino patients face in ACP participation (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Kelley et al., 2010; Loggers et al., 2013; Nedjat-Haiem et al., 2017).

Considering these identified gaps in the literature, this study aims to qualitatively assess ACP preferences, experiences, and comfort in EOL care discussions among elderly Latino patients in an urban, outpatient setting.

Methods

This study took place in the geriatric primary care clinic at Los Angeles County + University of Southern California (LAC+USC) Medical Center over the course of 18 months (9/2014–3/2016), with counseling sessions occurring once a week. LAC+USC is an academic county hospital and outpatient care network in urban Los Angeles. Patients served by the geriatrics clinic are primarily Latino,

historically uninsured or underinsured, and over the age of 65. Primary care providers (PCP) referred all patients to the study at the conclusion of the patient's scheduled appointment. All patients with appointments on days the recruitment team was present were invited to participate in the study. Study team members - including medical students, residents, and geriatric medicine fellows - received training on facilitating EOL discussions and using the *Five Wishes* tool through workshops conducted by palliative care and geriatrics attending physicians at LAC+USC. These workshops included instruction on appropriate phrasing, tone, and interpretations of questions addressed in the *Five Wishes*, as well as document administration.

Aging With Dignity, a private, non-profit organization developed the *Five Wishes* tool in order to provide a user-friendly advance planning resource that appeals to populations with diverse cultures, languages and faith traditions (Aging With Dignity, 2017). This document was chosen for this intervention as it meets the legal requirements for an AD in most of the U.S. (including California), is available in English and Spanish, and facilitates a guided conversation about EOL care, including items addressing comfort, dignity, and spirituality. Furthermore, although *Five Wishes* is the most widely used AD in the country, there is little research about its utility, feasibility, or efficacy.

Counseling sessions with patients were held in private consultation rooms in the geriatric primary care clinic. Patients could elect to bring family members or caregivers to the sessions and physicians were explicitly instructed to honor these choices. Discussions with non-English speaking patients were conducted by bilingual counselors or with professional medical interpretation services, and a *Five Wishes* AD in the patient's preferred language was used if patients elected to complete an AD.

After obtaining informed consent, a pre-session survey was administered to assess patient demographics, medical status, current attitudes and knowledge about EOL care. Patients were then invited to complete the *Five Wishes* document with a trained counselor. Patients who declined the counseling session were given the option to take a copy of the AD for later completion.

Information on EOL care was provided to all patients, regardless of their decision to complete an AD. Whether the AD was completed with the counselor or the patient elected to complete the document later, a post-session survey was administered to assess satisfaction with the counseling experience and changes in attitudes and knowledge regarding EOL care. Patients took home their completed AD and a copy was retained for inclusion in the medical record. Survey data was then aggregated to (1) generate a demographic and medical profile of the patients and (2) assess attitudes and perspectives regarding EOL care, both before and after receiving individualized ACP counseling. An IRB was obtained for this study (reference number HS-14-00535).

Results

Patient characteristics

A total of 41 patients were consented to participate in the study, and their demographic information is summarized in Table 1. Patients were primarily Hispanic/Latino (95%), Spanish-speaking (95%), and female (63%). Among the 41 completed counseling sessions, 39 were conducted in Spanish, with bilingual counselors or professional medical interpretation services, and two were conducted in

English. Patients 70–79 years of age comprised 36% of the sample population, and 44% were 80 years of age or older. Most patients (61%) self-reported at least 3 chronic medical conditions, mainly hypertension (51%), hyperlipidemia (37%), diabetes (34%), and arthritis (32%). Almost one-third reported depressive symptoms (29%). Few patients reported a recent hospitalization (7% in the past 30 days), and 58% described their current state of health as either “excellent” or “good.” Among patients that consented to participate, 61% had family members present with them at their clinical appointment, and 100% of these patients invited family to participate in the ACP session.

Advance directive knowledge: Pre-session survey

Nearly all participants (95%) had never documented their wishes for EOL care, and only 24% reported having ever discussed EOL care wishes with family or others, including health care providers. Few patients felt that the best time to have initial EOL care discussions was while dying or hospitalized for a life-threatening illness (7% and 2%, respectively). Conversely, 56% thought it best to discuss EOL care while still healthy. A similar percentage (54%) reported not knowing that there were EOL treatment options, but 83% said that it was “very important” to learn about these

Table 1. Characteristics of the study participants ($n = 41$).

| Characteristic | Number (%) | Characteristic | Number (%) |
|--------------------------------|------------|---|------------|
| Age (years) | | Number of chronic conditions | |
| 60–64 | 1 (2%) | None | 6 (15%) |
| 65–69 | 7 (17%) | 1–2 | 10 (24%) |
| 70–74 | 10 (24%) | 3–4 | 20 (49%) |
| 75–79 | 5 (12%) | ≥5 | 5 (12%) |
| 80–84 | 9 (22%) | Diagnoses | |
| ≥85 | 9 (22%) | Heart disease | 9 (22%) |
| Sex | | Hypertension | 21 (51%) |
| Female | 28 (68%) | Hyperlipidemia | 15 (37%) |
| Male | 13 (32%) | Diabetes | 14 (34%) |
| Racial/ethnic group | | Cancer | 4 (10%) |
| Latino/Hispanic | 39 (95%) | Chronic back pain | 12 (29%) |
| White | 1 (2%) | Arthritis | 13 (32%) |
| Asian | 1 (2%) | Depression | 12 (29%) |
| Primary language | | Other mental health | 1 (2%) |
| Spanish | 39 (95%) | Other | 9 (22%) |
| English | 2 (5%) | Recent hospitalization | |
| Current state of health | | (Past 30 days) | |
| Excellent | 7 (17%) | Yes | 3 (7%) |
| Good | 17 (41%) | No | 38 (93%) |
| Fair | 14 (34%) | Family member present at ACP session | |
| Poor | 3 (7%) | Yes | 25 (61%) |
| | | No | 16 (39%) |

Table 2. Pre-session survey results ($n = 41$).

| Survey question | Number (%) |
|--|------------|
| How comfortable are you talking about your wishes/goals for care at the EOL? | |
| Comfortable | 27 (66%) |
| Neither comfortable nor uncomfortable | 9 (22%) |
| Uncomfortable | 3 (7%) |
| Does not know | 2 (5%) |
| Have you ever written down any thoughts about your wishes for EOL plans? | |
| Yes | 2 (5%) |
| No | 39 (95%) |
| Have you talked about your wishes for care at the EOL with anyone? | |
| Yes | 10 (24%) |
| No | 31 (76%) |
| When do you think it is the best time to discuss your wishes/goals for care at the EOL? | |
| Before getting sick, while healthy | 23 (56%) |
| When first diagnosed with a life-threatening illness | 3 (7%) |
| When first sick from a life-threatening illness | 3 (7%) |
| When hospitalized for a life-threatening illness | 1 (2%) |
| If dying | 3 (7%) |
| All of the above | 2 (5%) |
| Never | 1 (2%) |
| Does not know | 5 (12%) |
| Did you know that you have options for accepting or rejecting EOL treatment? | |
| Yes | 16 (39%) |
| No | 22 (54%) |
| Does not know | 3 (7%) |
| How important is to you to learn about options for EOL treatment? | |
| Very important | 34 (83%) |
| Somewhat important | 4 (10%) |
| Not important | 3 (7%) |

options. Results from the pre-session survey are presented in [Table 2](#).

A total of 36 patients completed an AD with a counselor and five declined (one had time constraints, two wished to discuss with family who were not present, one wanted to read the AD independently, and one did not specify a reason). [Table 3](#) summarizes the treatment preferences selected by patients in their completed ADs. Most patients agreed with the statement: “I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms” in the cases of being close to death (73%); in a coma and not expected to wake up or recover (55%); or with severe brain damage and not expected to recover (61%). Few patients did not want life support treatment started in any case if close to death (12%); in a coma and

Table 3. EOL treatment decisions ($n = 33$)*.

| Scenario | Number (%) |
|--|------------|
| Close to death | |
| I want to have life-support treatment | 5 (15%) |
| I do not want life-support treatment. If it has been started, I want it stopped. | 4 (12%) |
| I want to have life-support treatment only if my doctor believes it could help. | 24 (73%) |
| Permanent and severe brain damage and not expected to recover | |
| I want to have life-support treatment | 6 (18%) |
| I do not want life-support treatment. If it has been started, I want it stopped. | 7 (21%) |
| I want to have life-support treatment only if my doctor believes it could help. | 20 (61%) |
| In a coma and not expected to wake up or recover | |
| I want to have life-support treatment | 6 (18%) |
| I do not want life-support treatment. If it has been started, I want it stopped. | 9 (27%) |
| I want to have life-support treatment only if my doctor believes it could help. | 18 (55%) |

*5 participants declined to complete an AD at the time of the counseling session (see Results section for explanations). Three out of 36 completed ADs were not found in the electronic medical record at time of analysis; these three ADs were omitted above.

not expected to wake up or recover (27%); or with permanent and severe brain damage and not expected to recover (21%).

Advance directive knowledge: Post-session survey

Most participants reported they appreciated the opportunity to talk about EOL treatment options (95%). Nearly half hoped her/his doctor would have talked about EOL treatment sooner (44%). The majority reported a better understanding of EOL care wishes (66% completely agree) and 85% reported feeling more comfortable speaking about their EOL care wishes after discussing EOL care options or completing the AD, compared to 66% in the pre-session survey. Results from the post-session survey are summarized in [Table 4](#).

Discussion

This study demonstrates that most patients in a sample of primarily Latino, Spanish-speaking patients at an urban care facility had not previously discussed or documented ACP wishes. Most patients, however, appreciated the opportunity to learn about care options, and nearly half hoped their physician would have discussed EOL wishes

Table 4. Post-session survey results (n = 39)*.

| Survey question | Number (%) |
|--|------------|
| After this session, I feel that I have a better understanding of my wishes for care at the EOL. | |
| Completely agree | 27 (66%) |
| Somewhat agree | 8 (20%) |
| Neither agree nor disagree | 1 (2%) |
| Somewhat disagree | 0 (0%) |
| Completely disagree | 0 (0%) |
| (Did not answer) | 3 (7%) |
| After this session, how comfortable are you talking about your wishes/goals for EOL care? | |
| Comfortable | 35 (85%) |
| Neither | 3 (7%) |
| Uncomfortable | 0 (0%) |
| Does not know | 1 (2%) |
| I had hoped my doctor would have talked with me about this sooner. | |
| True | 18 (44%) |
| False | 19 (46%) |
| Neutral or does not know | 2 (5%) |
| I appreciated the chance to talk about EOL treatment options today. | |
| True | 39 (95%) |
| False | 0 (0%) |

*2 participants (5%) declined to complete the post-session survey.

sooner. Goals of care discussions revealed that most patients expressed a desire for a trial of life supporting treatment if it facilitated recovery, but most would otherwise decline medical intervention. Most patients expressed a desire to cease life-supporting interventions in the hypothetical absence of possible recovery, underscoring the importance of provider communication in EOL counseling.

These findings confirm expectations that elderly Latino patients have limited exposure to ACP, and most have not documented EOL wishes (Eleazer et al., 1996; Kiely, Mitchell, Marlow, Murphy, & Morris, 2001; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Murphy et al., 1996). Despite this limited exposure to ACP, patients clearly expressed a desire to discuss EOL wishes and felt comfortable doing so. Furthermore, previous studies affirm a general desire within the Latino community for a conservative approach to life supporting treatment. The vast majority of elderly Latino patients prefer comfort-focused EOL care, including refusal of a ventilator, feeding tube, or CPR (Kelley et al., 2010). In regards to optimal timing for EOL discussions, a preference for early physician-led discussions is consistent with previous findings that many elderly patients, irrespective of race/ethnicity, hope for these conversations

at routine clinic visits (Caralis, Davis, Wright, & Marcial, 1993; Sharp et al., 2013).

Utilizing culturally sensitive resources such as bilingual counselors and ADs in the patients' preferred language could positively impact a patient's experience with ACP counseling. Previous studies have highlighted the potential impact of improving provider communication in ACP, including education that is culturally sensitive and accessible to persons with low health literacy (Fischer, Sauaia, Min, & Kutner, 2012). Efforts to increase Latino patients' completion of ADs with culturally sensitive educational materials and Spanish-language ADs have also had moderate success (Sudore et al., 2007). The inclusion of family members in ACP discussions may also be an important factor in AD completion for Latino patients, as both our study and previous studies suggest that many patients prefer to have family members present when making important medical decisions (Kelley et al., 2010). Offering patients the choice to include family and respecting their input are important clinical practices in every encounter. High numbers of completed preferred-language ADs in this study illustrates the potential of individualized counseling to improve patient comfort in discussing and documenting care goals.

This study has several limitations. The small sample size and collection of data from a single clinical site limits generalizability. Future studies should attempt to recruit a larger sample of patients from diverse clinical sites. Additionally, our study did not attempt to distinguish cultural or religious values between the diverse origin groups (i.e. Mexicans, Cubans, Puerto Ricans, etc.) that comprise the Latino population. Previous studies suggest that certain factors such as strong identification with Catholicism, for instance, is associated with decreased ACP utilization and AD completion (Shen et al., 2016). Future studies should clarify whether there are significant distinctions in EOL preferences between these groups. Acculturation measures were also not taken into account in our analysis. Future studies should examine whether acculturation to the U.S. significantly changes attitudes toward EOL goals with increased time of residence. Use of acculturation tools, such as those mentioned in Wallace et al.'s review, could strengthen future studies (Wallace,

Pomery, Latimer, Martinez, & Salovey, 2010). Lastly, future studies may consider collecting data to calculate Charlsson comorbidity scores for each participant so as to improve outcome comparability to other studies, as well as between participant groups with varying illness severity.

Despite these limitations, findings from this study help expand the currently limited literature on Latino EOL care and offer clinical strategies to facilitate important ACP discussions in an outpatient setting. Busy clinic schedules often curtail the extent to which physicians can dedicate necessary time and care to these important discussions. Our counselors successfully utilized a “warm hand-off” method, in which care was directly transferred from a patient’s PCP to members of the counseling team. In doing so, counselors were able to build upon existing rapport and ease care transition. This practice and the use of trained counselors may provide busy clinics a means of providing ACP services without shortening discussions or interrupting clinic flow. Indiscriminately offering counseling to all patients, regardless of health status, is also critical in ensuring that patients do not feel targeted or singled-out. Additionally, as of January 1, 2016, the Centers for Medicare & Medicaid Services (CMS) began reimbursing for ACP as a payable service for traditional Medicare beneficiaries. This may incentivize clinicians or other qualified health care professionals to dedicate more time to ACP discussions.

Most reviews emphasize that cultural diversity has profound effects on EOL decision-making processes, yet clinicians have a limited evidence base to guide the development of culturally sensitive approaches (Krakauer, Crenner, & Fox, 2002). Our study demonstrates a need to improve cultural competency training for medical providers to enhance the impact of EOL discussions, and better prepare providers to counsel Latino patients in death and dying issues. In addition to language, cultural nuances about EOL, death and spirituality should be taken into consideration as they impact willingness to fill out ADs. Honoring and respecting the role of family members is also important as family-centered decision-making plays a prominent role in Latino culture. Additionally, though understanding cultural themes is important, providers should avoid stereotyping as

not all people of one heritage are alike or have acculturated the same; thus, it is critical that each patient be regarded as an individual. By illustrating preferences and desires for ACP counseling and initiation of conversations earlier in routine primary care, we hope clinicians may more confidently incorporate EOL conversations in everyday practice.

Clinical Implications

- Offer to discuss and document a patient’s EOL wishes during regular primary care appointments, regardless of health status.
- Ensure that counseling is completed in the patient’s preferred language, using culturally competent materials, and with family members present if this is the patient’s preference.
- Provide cultural-competency training for medical providers to enhance the impact of EOL discussions and improve ACP completion rates for Latino patients.

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Disclosure statement

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Notes on contributors

Lauren Y Maldonado: Led study design, protocol/IRB writing, and data collection during the first year of the study, in collaboration with EMJ. Drafted the abstract, introduction and discussion with RBG. Took responsibility for editing the manuscript in its entirety with RBG. Takes overall responsibility for the integrity of this paper. Shares first authorship with RBG.

Ruth B. Goodson: Assumed leadership during the second year of the study. Translated study materials, including questionnaires and consent forms, into Spanish. Drafted the abstract, introduction and discussion with LYM. Took responsibility for all edits of the paper with LYM. Shares first authorship with LYM.

Matthew C. Mulroy: Led data analysis and drafted the results.

Emily M. Johnson: Led study design and data collection during the first year of the study in collaboration with LYM. Assisted with data analysis and drafted the methods.

Jo Marie Reilly: Served as a mentor to the study team and provided technical support and expertise throughout study implementation, analysis and manuscript writing.

Diana C. Homeier: Provided technical support and expertise throughout study implementation, analysis and manuscript writing. Served as lead clinical contact, study mentor, and liaison between study team and clinical staff at the LAC+USC Geriatrics Clinic.

ORCID

Lauren Y Maldonado  <http://orcid.org/0000-0002-8352-0815>

Emily M Johnson  <http://orcid.org/0000-0002-0169-4353>

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