

# Rural Dementia Caregivers in Southwest Texas

## An Exploratory Study of Advance Directives and End-of-Life Proxy Decision Making

Jung Kwak, PhD, MSW; Bo Xie, PhD; Jane D. Champion, PhD, DNP, FNP, FAANP, FAAN; and Kenneth R. Fleischmann, PhD

### ABSTRACT

For a growing number of persons with dementia (PWDs), advance care planning

#### ABOUT THE AUTHORS

*Dr. Kwak is Associate Professor, Dr. Xie is Professor, and Dr. Champion is Professor, School of Nursing, and Dr. Fleischmann is Professor, and Dr. Xie is also Professor, School of Information, The University of Texas at Austin, Austin, Texas.*

*The authors have disclosed no potential conflicts of interest, financial or otherwise.*

*The current study was part of a pilot research grant from the population health initiative at the University of Texas at Austin, entitled Values and Preferences in Dementia Family Caregivers End-of-Life Decision Making (principal investigator [PI] B.X.; co-PIs, K.R.F., J.K.).*

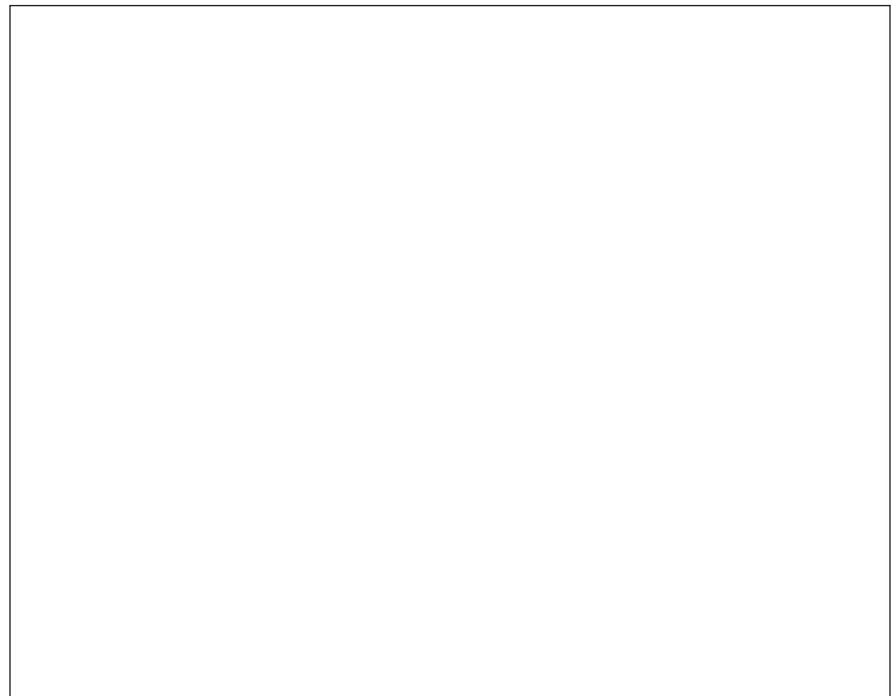
*The authors thank the caregivers who participated in the study, and biostatistician Dr. Adama Brown and graduate research assistant (GRA) Ya-Ching Huang in the Cain Center of the School of Nursing and GRA Kolina Koltai in the School of Information for their assistance with data entry. Editorial support with article development was provided by the Cain Center for Nursing Research and the Center for Transdisciplinary Collaborative Research in Self-Management Science (P30, NR015335) at the University of Texas at Austin School of Nursing.*

*Address correspondence to Jung Kwak, PhD, MSW, Associate Professor, School of Nursing, The University of Texas at Austin, 1710 Red River Street, Mail Code: D0100, Austin, TX 78701; e-mail: jkwak@nursing.utexas.edu.*

*Received: March 9, 2019*

*Accepted: May 1, 2019*

*doi:10.3928/00989134-20190530-01*



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(ACP) can help families make important end-of-life (EOL) care decisions that reflect PWDs' values and preferences. The current exploratory study aimed to understand advance directive planning and decision making among PWDs and caregivers. A survey was conducted with a convenience sample of 47 ethnically diverse PWD caregivers recruited from rural health care facilities in Southwest Texas. Sixty-eight percent of PWDs and caregivers were Hispanic. The majority of PWDs had completed an advance directive (60%) and preferred equally shared decision making between family (including the PWD) and physicians (57%). Under a hypothetical EOL scenario for PWDs, caregivers chose comfort (40%) and palliative care treatment (55%) more than other goals and treatment options. In this scenario, Hispanic PWDs were less likely than non-Hispanic White counterparts to complete an advance directive (48% vs. 81%,  $p < 0.05$ ) and to choose only pain and symptom management (46% vs. 81%,  $p < 0.05$ ). Although the overall ACP rates among rural PWDs may be comparable to those for the general PWD population, ethnic differences exist.

More culturally competent education efforts are needed to promote ACP among PWDs in culturally diverse rural communities. [Journal of Gerontological Nursing, x(x), xx-xx.]

**A**lzheimer's disease and other dementias are the sixth leading cause of death in the United States, accounting for one third of all deaths among U.S. older adults in 2016 (Alzheimer's Association, 2018). Due to progressive memory loss and other cognitive impairments associated with dementia, it is important for persons with dementia (PWDs) and their family members to engage in advance care planning (ACP) early in the disease process. During ACP, individuals with dementia are encouraged to complete advance directives such as a *living will* (which specifies preferences for life support) and *durable power of attorney for health care* (which designates proxy decision makers for medical decisions). ACP can help PWDs discuss their values and preferences with family members and health care providers, record their wishes, and help their designated health care proxies. Often a family member makes decisions reflecting PWDs' values when PWDs can no longer make their own decisions at the end of life (EOL) (Dixon, Karagiannidou, & Knapp, 2018).

However, little is known about the experience of ethnically diverse PWDs and families, especially those living in rural areas. Approximately 14% of U.S. residents, 46.2 million of a total 316 million, live in rural areas, which cover 72% of the nation's geography (U.S. Department of Agriculture Economic Research Service, 2017). For PWDs who live in rural areas, there may be special challenges to engaging in ACP because their remote locations have fewer health care providers and services, including palliative care and hospice (Ashcraft & Owen, 2016). Unique cultural factors may influence ACP in rural areas such as those near the border between Mexico and Southwest Texas, where there are

many Hispanic residents. Prior studies have documented lower rates of ACP participation among Hispanic individuals than among their non-Hispanic White counterparts (Ko, Lee, Ramirez, Lopez, & Martinez, 2018; Kwak & Haley, 2005).

Although, research suggests potential barriers to ACP and lower levels of ACP engagement among Hispanic residents in rural areas, no empirical study has explored ACP among Hispanic PWDs and families, as well as how family caregivers would make EOL care decisions for their relatives in rural communities. The current authors report an exploratory study of ACP and proxy decision making among PWDs and families in rural areas in Southwest Texas near the border with Mexico. The authors' goal was to understand PWDs' advance directive completion and the role of the family in proxy decision making in predominantly Hispanic rural communities.

## METHOD

A self-report survey was administered among a convenience sample of family caregivers of patients with memory problems or a diagnosis of Alzheimer's disease and related dementia. Family caregivers were recruited from outpatient family practice clinics near the border in South Texas where their relatives were receiving care. In the current study, *family caregivers* were defined as individuals who self-identify themselves as a family caregiver, or who have been caring for a relative by assisting with activities of daily living for at least 2 years. The clinics were in a predominately rural county with a population of 27,245, where 70% of the population was Hispanic individuals (U.S. Census Bureau, 2015). The county is designated by the U.S. Department of Health and Human Services (2002) as a *medically underserved area*, which is an area or population with too few primary care providers, high infant mortality, high poverty, or a high

older adult population.

To participate in the survey, participants had to be 18 or older, able to read and write in English, and self-identify as a family caregiver. A total of 47 caregivers completed the self-administered questionnaire during a 3-week period between April and May 2017. Participants were recruited verbally or from flyers posted at the research sites. During the survey, caregivers answered questions about their relatives' demographic and functional characteristics, ACP, and about their own preferences for proxy decision making for PWDs (including EOL care decisions). The survey took approximately 20 to 25 minutes to complete. Informed consent was obtained prior to data collection and each participant received a \$10 gift card upon completion of the instrument. The current study was approved by the University of Texas at Austin Institutional Review Board.

## Measures

Participants answered four questions that have been used in previous studies with caregivers of PWD or Parkinson's disease (Kwak, De Larwelle, Oconnell-Valuch, & Kesler, 2016). These questions were about whether the caregiver's relative had completed a living will, shared the living will with the caregiver, completed a durable power of attorney for health care, and selected the caregiver as the durable power of attorney for health care. Response options were *yes* = 1 or *no* = 0.

Caregivers were presented with a hypothetical EOL scenario with conditions likely to occur at the end stage of dementia. This scenario was adapted from studies concerning PWDs (Vollandes, Ariza, Abbo, & Paasche-Orlow, 2008) and their caregivers (Kwak et al., 2016). The EOL scenario included common end-stage dementia symptoms and indicated that the PWD's life expectancy was <1 year. Caregivers were asked to choose a goal of care and set of treat-

**TABLE 1**

**CHARACTERISTICS OF PERSONS WITH DEMENTIA (PWD) AND CAREGIVERS**

Characteristic	All (N = 47)	Hispanic (n = 31)	Non-Hispanic White (n = 16)	p Value
<b>Caregiver Characteristics</b>				
Mean age (years) (SD) (range)	52.6 (13.8) (27 to 85)	47.9 (11.9) (27 to 78)	58.5 (13.4) (37 to 85)	<0.05
Gender: female (n, %)	39 (83)	28 (90)	11 (69)	
Education (n, %)				<0.05
Less than high school	6 (13)	6 (19)	0	
Completed high school	13 (28)	10 (32)	3 (18.8)	
Attended or completed college or graduate school	25 (53)	12 (39)	13 (81.3)	
Mean months in caregiving (SD) (range)	32.3 (26.2) (2 to 96)	34.4 (29.1) (2 to 96)	28.2 (19.6) (4 to 60)	
<b>PWD Characteristics</b>				
Mean age (years) (SD) (range)	78.9 (9.2) (60 to 95)	77.3 (8.8) (60 to 91)	84.2 (8.1) (65 to 95)	<0.05
Gender: female (n, %)	37 (79)	24 (77)	13 (81)	
Education (n, %)				<0.05
Less than high school	23 (49)	21 (71)	1 (6.3)	
Completed high school	7 (15)	3 (10)	4 (25)	
Attended or completed college or graduate school	13 (28)	2 (6)	11 (68.8)	
Health insurance: Medicare (n, %)	38 (81)	26 (84)	12 (75)	
Health insurance: Medicaid (n, %)	19 (40)	16 (51.6)	3 (18.8)	<0.05
PWD is a parent to the caregiver (n, %)	37 (79)	26 (83.9)	12 (75)	
Living situation (n, %)				
Alone	12 (26)	8 (25.8)	4 (25)	
With the caregiver	9 (19)	5 (16.1)	4 (25)	
With another relative	15 (32)	11 (35.5)	4 (25)	
In a group home or nursing home	11 (23)	7 (22.6)	4 (25)	
Memory problem: yes (n, %)	39 (83)	24 (77.4)	15 (93.8)	
Dementia diagnosis: yes (n, %)	30 (64)	21 (68)	9 (56)	
Mean no. of months since diagnosis (SD) (range)	41.1 (42.7) (1 to 183)	39.9 (48) (1 to 183)	43.9 (28.8) (3 to 77)	
Severity (n, %)				<0.05
Not at all	15 (32)	13 (41.9)	2 (12.5)	
A little	10 (21)	6 (19.4)	4 (25)	
Moderate	15 (32)	10 (32.3)	5 (31.3)	
Very to extreme	4 (9)	0	4 (25)	
Mean activities of daily living score (SD) (range)	11.8 (5.8) (6 to 24)	12.2 (6.13) (6 to 24)	10.3 (4.4) (6 to 24)	
Mean instrumental activities of daily living score (SD) (range)	26.6 (9.3) (11 to 40)	27.1 (9.7) (11 to 40)	25.4 (8.9) (14 to 37)	

*Note.* Percentages may not add up to 100 due to missing values. Activities of daily living scale has six items with each item scoring 1 to 4; possible score ranges from 6 to 24, with higher scores indicating more dependence. The instrumental activities of daily living scale has 10 items with each item scoring 1 to 4; possible score ranges from 10 to 40, with higher scores indicating more dependence.

ment options (Vollandes et al., 2008) for their relative as the PWD within the scenario. The three options for goal of care were: life-prolonging care; limited care, which focuses on maintaining current physical and mental functions but not extending life; and comfort only care. The three options for treatments included performing everything available, performing everything except for cardiopulmonary resuscitation (CPR) or procedures used in the intensive care unit (ICU), and performing only procedures for pain and symptom control.

Caregivers were also asked two questions about medical decision making for their relative. The first question was: "Within the family, who makes health care decisions for your relative?" Response options included *my relative alone*, *mostly my relative*, *my relative and myself and/or other family members equally*, *mostly myself and/or other family members*, and *myself and/or other family members alone*. The second question was: "Who do you think should make health care decisions for your relative's condition?" Response options included the *health care provider alone*, *mostly the health care provider*, *the health care provider and the family equally*, *mostly the family*, and *the family alone*. *Health care provider* was defined as physician, nurse, and/or other health care professional. *Family* was defined as "your relative, you, and/or other members of your relative's family who have a role in making decisions for your relative."

### Data Analysis

Descriptive statistics were used to examine sociodemographic, functional, and advance directive characteristics of PWDs and caregivers, as well as caregivers' choices for PWDs' EOL care goals and treatments in the hypothetical scenario. Other findings from the current study were reported elsewhere (Xie, Champion, Kwak, & Fleischmann, in press). All analyses were performed

with SPSS version 25.0.

### RESULTS

The final sample of caregivers included a total of 47 participants who identified themselves as non-Hispanic White (34%) or Hispanic and not White (66%) (Table 1). Caregivers have been caring for their relatives for an average of 32 months ( $SD = 26.2$  months). Approximately 70% of caregivers were caring for their parents (data not shown). Hispanic caregivers were younger than White caregivers (mean age = 47.9,  $SD = 11.9$  years vs. mean age = 58.5,  $SD = 13.4$  years,  $p < 0.05$ ), and not likely to have attended or completed college or graduate school (42.9% vs. 81.3%,  $p < 0.05$ ). Hispanic PWDs were younger than White PWDs (77.3 vs. 84.2 years,  $p < 0.05$ ), not likely to have attended or completed college or graduate school (7.4% vs. 68.8%,  $p < 0.05$ ), and more likely to be on Medicaid (51.6% vs. 18.8%,  $p < 0.05$ ). Fewer Hispanic PWDs than White PWDs had moderate to high memory problems (32.3% vs. 56.3%,  $p < 0.05$ ).

As shown in Table 2, more than one half of PWDs had completed a living will (60%) and made legal arrangements to designate a health care power of attorney (60%). Hispanic PWDs were less likely than White PWDs to have completed a living will (45% vs. 88%,  $p < 0.05$ ) or to have designated a health care power of attorney (48% vs. 81%,  $p < 0.05$ ).

Thirty-six percent of caregivers reported that the PWD, caregiver, and family members made decisions equally, although 46% of caregivers reported that either family members or caregivers made medical decisions for patients. Approximately 57% of caregivers reported that medical decisions for the PWD should be made equally by the health care provider and family.

When caregivers were asked about goals of care and treatment options,

the choices of treatment options varied between Hispanic and White caregivers. Approximately 81% of White caregivers chose the option to perform only procedures for pain and symptom control, whereas 42% of Hispanic caregivers chose this option. Higher proportions of Hispanic caregivers as opposed to White caregivers chose the options to perform everything available (29% vs. 0%) and to perform everything except for CPR or procedures used in the ICU (26% vs. 13%).

### DISCUSSION

In the United States, the populations of PWDs and Hispanic older adults are growing rapidly. Given the progressive nature of dementia and the higher risk of dementia among older Hispanic individuals (Alzheimer's Association, 2018), it is essential for health care providers to effectively support this growing group to engage in communication and planning for their future health care, including ACP.

In the current study, more than one half of PWDs (60%) reported having completed a living will or designated a health care power of attorney. The advance directive completion rates of this sample are somewhat similar to rates reported in other studies with PWDs (65% completion rate reported in the current study [Lingler et al., 2008]), but higher than rates in studies with rural samples (32% [Ashcraft & Owen, 2016]). The ACP literature (Institute of Medicine, 2015) has consistently documented that older adults with health problems are likely to engage in ACP than those without health problems. It may be that as dementia affects cognitive and functional health progressively, even PWDs in rural areas are likely to be encouraged to engage in ACP with increasing recognition of the need for family members and health care providers to be actively engaged in medical decision making. For example, most caregivers pre-

**TABLE 2**

**ADVANCE CARE PLANNING AND MEDICAL DECISION MAKING BY PERSONS WITH DEMENTIA (PWD) AND CAREGIVERS**

Variable	n (%)			p Value
	All (N = 47)	Hispanic (n = 31)	Non-Hispanic White (n = 16)	
<b>PWD's Advance Care Planning</b>				
PWD completed a living will	28 (60)	14 (45)	14 (88)	<0.05
Shared a copy of a living will with the caregiver	20 (71) <sup>a</sup>	11 (79) <sup>a</sup>	9 (64) <sup>a</sup>	
PWD designated a health care power of attorney	28 (60)	15 (48)	13 (81)	<0.05
Caregiver is the health care power of attorney	18 (62) <sup>b</sup>	8 (53) <sup>b</sup>	10 (77) <sup>b</sup>	
<b>Medical Decision Making for PWD's Care</b>				
How medical decisions for the PWD are made within the family				
Relative alone	2 (4)	2 (6)	0	
Mostly relative	3 (6)	2 (6)	1 (6)	
Relative and myself and/or other family members equally	17 (36)	12 (39)	5 (31)	
Mostly myself and/or family members	11 (23)	6 (19)	5 (31)	
Mostly myself and/or other family members alone	11 (23)	7 (23)	4 (25)	
How medical decisions for the PWD should be made				
Health care provider alone	0	0	0	
Mostly health care provider alone	3 (6)	3 (10)	0	
Health care provider and family equally	27 (57)	16 (52)	11 (69)	
Mostly family	10 (21)	6 (19)	4 (25)	
Family alone	5 (11)	5 (16)		
Treatment the caregiver would choose for the PWD in the scenario				
Life prolonging	9 (19)	8 (26)	1 (6)	
Limited care	17 (36)	12 (39)	5 (31)	
Comfort only	19 (40)	10 (32)	9 (56)	
Treatment the caregiver would choose for the PWD in the scenario				<0.05
Everything available	9 (19)	9 (29)	0	
Everything except for CPR/ICU	10 (21)	8 (26)	2 (13)	
Only pain and symptom control	26 (55)	13 (42)	13 (81)	

Note. CPR = cardiopulmonary resuscitation; ICU = intensive care unit.

<sup>a</sup> Percentage shows the proportion of PWDs who shared a copy of the living will with the caregiver among those who have a living will.

<sup>b</sup> Percentage shows the proportion of PWDs whose health care power of attorney is the caregiver among PWDs who designated a health care power of attorney.



ferred medical decisions for the PWD be made equally by the health care provider and family, and one half of caregivers reported that medical decisions for the PWD were made mostly by the caregiver or family members.

Regarding ethnic differences, the results of the current study support the findings of prior descriptive research. Hispanic PWDs in the current study were less likely to have advance directives, and Hispanic caregivers were likely to choose curative treatments for PWDs under the EOL scenario. Hispanic individuals may be reluctant to talk with someone about EOL care planning because discussion about EOL topics is discouraged (Kwak, Ko, & Kramer, 2014). An emphasis on respect for health care providers and family-centered decision making, as well as disparities in access to information and resources regarding ACP, may also serve as factors influencing ACP and EOL decision making among Hispanic individuals (Ko et al., 2018; Kwak & Haley, 2005).

## LIMITATIONS

Several limitations of the current study should be noted. The cross-sectional design with a small convenience sample of caregivers limits generalizability. The small sample prevented multivariate analysis to further examine the unique role of ethnicity or culture while controlling for group differences in key characteristics (i.e., PWDs' age, education, cognitive impairment, and Medicaid status). In addition, PWDs' preferences for EOL care as expressed by caregivers are only a proxy for actual decision making. Finally, PWDs' preferences were obtained from caregivers because the authors did not have access to actual advance directive documents.

## IMPLICATIONS

Despite these limitations, the authors' findings provide implications for clinical practice and research. Although participation in

ACP is lower for Hispanic PWDs than for their White peers, the rates of ACP participation for both groups were still higher than those reported among rural older adults. Hispanic PWDs may be likely to consider and plan for EOL care if further efforts are made by nurses and other health care team members to develop and deliver culturally sensitive ACP support and palliative care programs and services. Nurses can help patients and families reflect on their values and integrate them into their care planning. Nurses and other health care providers can improve their skills for engaging in ACP by using many available resources, including a training video developed by the Centers for Disease Control and Prevention (2015) for health care and aging services professionals, to consider their roles in ACP for older adults. In addition, the Conversation Project (access <https://theconversationproject.org>) provides useful tools and training resources on ACP, including resources for PWDs. With necessary skills to facilitate ACP conversations, nurses can focus their efforts to engage PWDs and family members in education about dementia care, including the trajectory of dementia and the need for future care planning. Culturally sensitive training curricula should reflect the importance of family involvement, including whom they want to be present in discussions about EOL and how they want to receive information.

## CONCLUSION

Future studies should further assess ACP and actual EOL decision-making situations by using prospective, mixed methods designs with more representative samples of Hispanic PWDs and family caregivers across regions to provide a fuller picture of ACP practices and the role of ethnicity and culture. Important questions that should be explored include who initiates the ACP process among culturally diverse PWDs and their fami-

lies, which topics are discussed, how much PWDs and family members are engaged in the discussion, and if these discussions are facilitated by health care providers. Furthermore, as ACP is a continuous dynamic process that needs to be revisited throughout the trajectory of dementia, there is a need for prospective studies to examine if and how PWDs and family caregivers revisit their preferences for EOL care and discuss them with health care providers over time. Findings from such studies can help inform development of targeted intervention approaches to promote ACP among culturally diverse groups of PWDs and families across the dementia trajectory.

## REFERENCES

- Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 14, 367-429. doi:10.1016/j.jalz.2018.02.001
- Ashcraft, A.S., & Owen, D.C. (2016). End-of-life planning in a rural elderly cohort. *Geriatric Nursing*, 37, 71-74. doi:10.1016/j.gerinurse.2015.11.009
- Centers for Disease Control and Prevention. (2015). *Advance care planning course*. Retrieved from <https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html>
- Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: A systematic review and critical discussion. *Journal of Pain and Symptom Management*, 55, 132-150.e1. doi:10.1016/j.jpainsymman.2017.04.009
- Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Retrieved from <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
- Ko, E., Lee, J., Ramirez, C., Lopez, D., & Martinez, S. (2018). Patient-family EoL communication and its predictors: Reports from caregivers of Latino patients in the rural U.S.-Mexico border region. *Palliative & Supportive Care*, 16, 520-527. doi:10.1017/s147895151700092x
- Kwak, J., De Larwelle, J.A., Oconnell-Valuch, K., & Kesler, T. (2016). Role of advance care planning in proxy decision making among individuals with dementia and their family caregivers. *Re-*

- search in *Gerontological Nursing*, 9, 72-80. doi:10.3928/19404921-20150522-06
- Kwak, J., & Haley, W.E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45, 634-641. doi:10.1093/geront/45.5.634
- Kwak, J., Ko, E., & Kramer, B.J. (2014). Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the USA: Perspectives of care managers on challenges and recommendations. *Health and Social Care in the Community*, 22, 169-177. doi:10.1111/hsc.12073
- Lingler, J.H., Hirschman, K.B., Garand, L., Dew, M.A., Becker, J.T., Schulz, R., & DeKosky, S.T. (2008). Frequency and correlates of advance planning among cognitively impaired older adults. *American Journal of Geriatric Psychiatry*, 16, 643-649. doi:10.1097/JGP.0b013e31816b7324
- U.S. Census Bureau. (2015). *Quickfacts Uvalde County, Texas*. Retrieved from <https://www.census.gov/quickfacts/uvaldecountytexas>
- U.S. Department of Agriculture Economic Research Service. (2017). *Population and migration*. Retrieved from <https://www.ers.usda.gov/topics/rural-economy-population/population-migration.aspx#.U8hDk1YIKnB>
- U.S. Department of Health and Human Services. (2002). *MUA find*. Retrieved from <https://data.hrsa.gov/tools/shortage-area/mua-find>
- Volandes, A.E., Ariza, M., Abbo, E.D., & Paasche-Orlow, M. (2008). Overcoming educational barriers for advance care planning in Latinos with video images. *Journal of Palliative Medicine*, 11, 700-706. doi:10.1089/jpm.2007.0172
- Xie, B., Champion, J.D., Kwak, J., & Fleischmann, K.R. (in press). Mobile health, information preferences, and surrogate decision-making preferences of family caregivers of persons with dementia in rural Hispanic communities: A pilot study. *Journal of Medical Research*.