Spring 5-15-2019

Advance Care Planning Interventions for Racially and Ethnically Diverse Populations: A Literature Review

Haley Kirkpatrick
hkirkpatrick1@yahoo.com

Advance Care Planning Interventions

For Racially and Ethnically Diverse Populations: A Literature Review

Haley Kirkpatrick, FNP

4056 Fiora Place Lafayette, CA 94549

Hkirkpatrick1@yahoo.com

916-205-9182

Anticipated date of graduation with DNP is May 2020

University of San Francisco

2130 Fulton St. San Francisco, CA 94117

Currently employed by Contra Costa County Health Services in Antioch, CA

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Abstract

Background and purpose: Diverse populations are less likely to engage in end-of-life-care-planning. This literature review examined research on end-of-life planning interventions for diverse patient populations.

Methods: This systematic search included Academic Search Complete, Cochrane, CINAHL, and PubMed databases. Results were limited to peer-reviewed articles published in English between 2015 to 2019.

Conclusions: Each intervention was effective at increasing advance care planning (ACP) engagement. Community-based programs are costlier. PREPARE used less resources. If diverse populations are specifically targeted, ACP engagement increases.

Implications for practice: Healthcare institutions and practitioners should employ targeted interventions for ACP engagement of diverse groups.

Keywords: end-of-life-care planning, diverse patients, advance directive, advance care planning, ACP interventions

Advance Care Planning Interventions for Racially and Ethnically Diverse Populations: A Literature Review

Introduction

As the U.S. geriatric population continues to increase and becomes more diverse, advance health care planning needs to be prioritized by the healthcare system in a culturally sensitive manner. By 2050 there will be an estimated 33 million African American, Hispanic, Asian, American Indian or Alaskan Natives age 65 years and older. This will be nearly 40% of the population for this age group (Ortman, Velkoff & Hogan, 2014). Nurse practitioners are increasingly at the frontline of primary and geriatric care for diverse and underserved populations, making this topic ever more significant for the NP workforce. The purpose of this paper is to review current literature regarding interventions aimed at increasing end-of-life-care-planning engagement and advanced directives for diverse and vulnerable patient populations.

The National Consensus Project for Quality Palliative Care has identified culturally sensitive end-of-life-care planning as a U.S. national priority (National Consensus Project for Quality Palliative Care, 2018). Unfortunately, the majority of individuals do not have an advance directive. Only one third of sick adults in the United States has completed an advance directive, indicating a significant lack of attention to end-of-life-care-planning (Reuters, 2017). Further, it is well documented that diverse populations are less likely to both engage in end-of-life-care planning and have an advance directive, when compared to Caucasian groups (Pecanac, Repenshek, Tennenbaum, & Hammes, 2014). One study found that only 18% of diverse patients had completed an advance directive compared to 34% of Caucasian participants (Rao, et al.,

2014). Health care providers are also less likely to engage in end-of-life discussions with diverse patients according to the research (Kulkarni, 2011).

Hong, Yi, Johnson, and Adamek (2018) in an attempt to identify challenges and promotors of advance care planning (ACP), conducted a systematic review of the current literature surrounding advance care planning among ethnic and racial minorities in the U.S. Their review identified the following four categories of facilitators and barriers to advance care planning: 1) socio-demographic factors, 2) health status, literacy, and experiences, 3) cultural values, and 4) spirituality (Hong et al., 2018). Socio-demographic factors influencing ACP engagement are age, income, and education. In regards to health status, the literature shows the more ill an individual, the more likely there is for ACP engagement (Hong et al., 2018). Ethnic and racially diverse groups more often report low health literacy about ACP in addition to how to complete an advance health directive (Hong et al., 2018). Acculturation and family-centered decision making tend to have a stronger influence on ACP engagement in diverse populations, which is also the case for spirituality and religion (Hong et al., 2018). The results of their review also indicate that when a targeted intervention regarding advance care planning is implemented, then engagement in end-of-life-planning improves for diverse groups (Hong et al., 2018).

Methodology

The systematic literature search for this article was conducted between February 2018 and April 2019, and the following databases were searched: Cochrane, CINAHL, Academic Search Complete, and PubMed. Search terms included *end-of-life-care-planning, advance care planning interventions, advance health directives, advance care planning programs, diverse*

patient populations, and *minority.* The author also reviewed several reference lists from advance care planning research articles.

This literature review included peer-reviewed, primary research articles that were written in English and conducted in the United States, were published within the past five years, and had an intervention specifically directed toward diverse ethnic and racial groups residing in the United States. Several articles reported research regarding lack of ACP engagement in diverse groups. However, if they did not examine a specific intervention aimed at diverse groups and ACP engagement they were excluded. Articles were included if advance directive completion was not specifically examined. This is due to the fact that completing an advance directive (AD) is actually quite cumbersome and is only one entity of ACP engagement on the ACP spectrum.

Advance care planning programs and minority groups yielded the largest number of articles from CINAHL with 77, but after review only one qualified for this literature review. Academic Search Complete had a return of 312 articles, five of which were included. PubMed had 104 articles, and after removal of duplicate articles, two were included. Cochrane did not provide any systematic reviews on ACP interventions targeting diverse groups. This exhaustive search yielded 11 articles that can be grouped into two categories related to advance care planning interventions: community focused programs and institutional based interventions. All of the evidence in this review was critically appraised with the John Hopkins Research Evidence Appraisal Tool. The results are displayed in Appendix A.

Results

Community Focused Advanced Care Planning Interventions

Huang et al. (2016) reported about the discrepancies in end-of-life planning among African Americans specifically from the southern U.S. Similar to Hong et al. (2018) they recognize this population has multiple co-morbidities in addition to low health literacy, making them a particularly vulnerable population. Huang et al. further acknowledges the lack of research regarding palliative care and African Americans.

Huang et al. (2016) conducted a mixed-method randomized control trial examining the Thinking Ahead Project (TAP). TAP is a single-session, ninety-minute intervention that employs motivational interviewing, Respecting Choices ACP facilitation program, The First Steps ACP protocol, and a revised advanced directive (AD) form that is written at a fifth-grade literacy level (Huang et al., 2016). The study population consisted of 30 community dwelling African Americans of which 15 were randomized to the intervention group and 15 were part of the control group. The control group received educational materials on AD and were asked to review the material on their own. A larger majority of the intervention group, 86.7%, reported feeling "very much" prepared to make decisions regarding end-of-life care, while only 66.7% of those in the control group reported the same level of preparedness (Huang et al., 2016). Finally, the revised form was well received by both groups, and 100% of both groups reported an increase in their intention to complete an AD (Huang et al., 2016).

Pecanac, Repenshek, Tennenbaum, and Hammes (2014) similarly utilized the Respecting Choices model of AD planning. Pecanac, et al. conducted a study with a retrospective chart review design to evaluate the Respecting Choices program with a racially diverse population. Developed in La Crosse County Wisconsin, the Respecting Choices program's effectiveness was initially tested with a mostly Caucasian population. Respecting Choices is a program with

several components including AD patient education materials for the community, AD facilitators working in all healthcare institutions within the community, standardization of policies regarding documentation and maintaining ADs, and performance improvement methods for each intervention (Pecanac et al., 2014).

With a study sample of the medical records of 732 deceased patients from 2005 to 2010, the authors examined what was written in an AD versus the actual treatment received (Pecanac et al., 2014). Upon chart review, the authors found a significant increase in advance directives for racially diverse patients, 25.8% to 38.4% with a p value of 0.011. However, there was not a statistically significant increase for the white population with a 46.7% to 47.3% change (Pecanac et al., 2014). This would indicate the Respecting Choices program has a potentially larger impact on racially diverse populations, although the specifics of the diverse population were not given in terms of exact breakdown of race and ethnicity.

Wilson, Kottke, and Schettle (2014) sought to increase ADs throughout the Minneapolis metropolitan area. Recognizing the success of the Respecting Choices program implemented in La Crosse, Wisconsin, the researchers sought to increase ACP documentation within a more complex and diverse population. Honoring Choices Minnesota (HCM) was therefore created by recruiting all healthcare systems within the Minneapolis metropolitan area.

According to Wilson et al. (2014), HCM consisted of three phases of implementation. Phase I, which included strategy and planning involved a three-year process of forming committees from various backgrounds including social workers, clinicians, and healthcare administration. Phase II was implementation of HCM. Several interventions were accomplished including the design of a website, online newsletter for health organizations, development of

seven pilot teams, a conference giving the opportunity to share experiences with HCM, and televised documentaries of ACP experiences on a local public television station. Phase III consisted of refinement and dissemination of the HCM plan. Six other communities across the nation adopted the HCM model. As of 2013, eight large metropolitan healthcare systems have implemented the HCM program. These efforts resulted in AD documentation rates ranging from 15.1% to 31.7%, reported from seven systems utilizing HCM (Wilson, 2014).

Sun et al. (2017) recognized the lack of end-of-life-care planning among Asian Americans. They designed a single group pre- and post-intervention design implementing a culturally-tailored education intervention. Study participants were recruited through their churches by way of announcements and telephone calls. Inclusion criteria were self-identifying as Chinese or Vietnamese and age 35 or older. Exclusion criteria were involvement with the project and prior completion of an AD. Program development involved nine individual interviews with church leaders and participating church members. The following was concluded regarding intervention content: (a) materials should be language-concordant; (b) health professionals should deliver messages; (c) sessions should be focused on patient rights to reduce the stigma associated with AD, and (d) enough time (4 weeks) should be provided between sessions to allow discussion between participants and family members.

Two educational sessions, 4 weeks apart, were conducted within four churches, two Chinese Protestant and two Vietnamese Catholic churches. The first session was a “spiritually-based endorsement of AD” by a church official and AD explanation by a physician (Sun et al., 2017). The second education session focused on AD explanation and completion. Pre- and post-intervention questionnaires were completed, and the primary outcomes were completion of an

AD and having an in-depth proxy conversation about AD (Sun et al., 2017). Descriptive statistics were computed for all measures. By three months post-intervention 71.8% of participants had completed an AD and 25% had a proxy conversation (Sun et al., 2017).

Nedjat-Haiem et al. (2017) examined the feasibility and satisfaction with a community-based ACP intervention in southern New Mexico, targeting older Latinos. They conducted a prospective, pretest/post-test, two group, randomized, community-based pilot project. Acknowledging their research was part of a bigger research project, the authors sought to evaluate the feasibility and satisfaction with the ACP-1 Plan. Study participants were recruited with methods from a sociocultural framework. Inclusion criteria were Latino/Hispanic living in southern New Mexico, age greater than 50, and having one or more chronic illnesses. A total of 104 subjects were enrolled. Participants were randomly assigned to usual care or treatment intervention group. The usual care group was given general advance directive education about ACPs and ADs. The treatment group received motivational interviewing counseling and client-centered supportive care regarding ACP engagement. The qualitative data indicated overall satisfaction with ACP-1 and feasibility of recruitment and the intervention (Nedjat-Haiem et al., 2017).

Institution Based Advanced Care Planning Interventions

Bonner et al. (2014), conducted a pilot study examining an advance care treatment plan (ACT-Plan) with African American dementia caregivers. Their group-based education intervention was conducted within five adult day care centers located in an urban setting. A two group, pre- and posttest design was utilized. Sixty-eight African American caregivers of relatives with dementia participated in one of two groups: a four-week ACT-Plan condition (n=35) or an

attention control condition focused on health promotion topics including hypertension, diabetes, exercise, and advance directives (n=33; Bonner et al., 2014). Randomization of participants did not occur.

Using a standard training protocol, each group session was conducted by an advance practice nurse. Using descriptive statistics, primary outcomes measured were knowledge about dementia, knowledge about cardiopulmonary resuscitation (CPR), mechanical ventilation (MV), tube feeding (TF), and self-efficacy on decisions made for CPR, MV, and TF. The authors concluded that knowledge of dementia and self-efficacy were increased for the ACT-Plan group. Comfort with knowledge of CPR, MV, and TF decreased in the ACT-Plan group, but remained unchanged in the attention control, suggesting more knowledge about these topics could make caregivers more uncomfortable about making decisions regarding these interventions (Bonner et al., 2014). Finally, there was a significant decrease in the decision to use CPR, MV, and TF in the ACT-Plan group, but not in the attention control group.

Song et al. (2016) conducted a secondary data analysis from a randomized control trial comparing an ACP intervention, Sharing Patient's Illness Representations to Increase Trust (SPIRIT), to usual care. Specifically, they examined dyad congruence on goals of care, surrogate decision-making confidence, a combination of the two, and patient decisional conflict (Song et al., 2016). Another comparison was made between the results of African Americans and Caucasians. Patients were recruited from 20 dialysis centers in eight counties in North Carolina. The SPIRIT arm participated in two sessions that discussed the participant's prognosis and values regarding end-of-life care. Involving a surrogate, a goals-of-care document was completed. Session two was a review of the goals-of-care (Song et al., 2016).

The SPIRIT intervention had a significant effect on the number of dyads congruent in goals of care, surrogate decision-making confidence, improving preparation for end-of-life decision making, and post-bereavement outcomes for African Americans. SPIRIT did not have a significant effect on Caucasians for the above listed outcomes. Indicating this program may be more aligned with African American cultural values (Song et al., 2016).

Sudore et al. (2014) developed the PREPARE Website in an attempt to "reconceptualize" advance care planning, especially for ethnically and racially diverse groups. PREPARE is a web-based tool that was designed to teach skills required to communicate end-of-life care wishes to a surrogate decision makers and primary care providers. There are five steps to PREPARE: 1) choose a medical decision maker and ask them to serve in that role; 2) decide what matters most in life for medical care; 3) decide on leeway for the surrogate decision maker; 4) communicate wishes with surrogates, clinicians, and other family and friends; and 5) ask doctors the right questions to make informed medical decisions. It is written at a fifth-grade level with a 14 point or larger font. The authors tested PREPARE's ability to engage older adults from racially and ethnically diverse backgrounds, in ACP, via a pilot study design. Forty-three participants were recruited of which 65% were non-white, and were asked to view PREPARE on their own within the senior center (Sudore et al., 2014). Engagement in ACP was the primary outcome and measured with the ACP Engagement Survey. ACP engagement was found to significantly increase at one week after the intervention (Sudore et al., 2014).

PREPARE was further tested by Sudore et al. (2017) within primary care clinics of the Veterans Affairs Health Care System. A randomized controlled trial was done to compare PREPARE with an easy to read advanced directive. Participants were randomized to either

PREPARE plus an AD or an AD alone. New ACP documentation at nine months was the primary outcome being measured. There was a total of 414 participants and 43% were non-white. New ACP documentation was 25% in the AD only arm, and 35% in the PREPARE plus AD arm. These findings suggest that PREPARE and an easy to read AD are capable of improving ACP engagement and documentation, specifically in resource challenged clinics.

PREPARE was again tested via a single-blind, parallel-group, comparative efficacy trial randomized at the patient level (Sudore et al., 2018). English-speaking and Spanish-speaking older adults were randomized to PREPARE and an easy-to-read advance directive intervention versus an easy-to-read AD alone. Outcomes evaluated were ACP documentation and engagement. A total of 986 older adults with a chronic illness from four primary care clinics were enrolled into the study. Similar to the RCT done at the Veterans Affairs Institution using PREPARE, the PREPARE group in this trial had higher new documentation of ACP at 15 months and documentation of legal forms. Further, the PREPARE arm also had a larger increase in ACP behavior change and action scores when compared to the AD-alone group.

Zapata et al. (2018) utilized the PREPARE movie version within a group visit setting, involving a diverse group of patients from a safety-net health system. This feasibility pilot included two 90-minute group visits that involved 22 participants viewing the PREPARE website movie while attending an ACP group visit. The majority of participants (73%) were nonwhite with limited health literacy. Knowledge about surrogate designation went from 46% pre-intervention to 85% post-intervention. The authors concluded there was an increase in surrogate designation and AD completion. Participants rated the group visits and PREPARE program a mean score of eight on a ten-point acceptability scale. Zapata et al concluded that

utilization of the PREPARE movie for ACP group visits for diverse adults, in the primary care setting, is feasible.

Conclusion

There is a discrepancy in the rate of advanced directives completed by Caucasian groups versus ethnically and racially diverse groups, with diverse groups having a lower rate of AD completion (Bullock, 2011; Huang et al., 2016; Pecanac et al., 2014). Multiple programs attempting to increase awareness, discussion, and completion of advanced directives are reported in the literature. Within this literature review, several models were examined including TAP, PREPARE, and HCM. TAP and HCM are models that require an abundance of financial and people resources. Although their results are promising, limited data has been received and even less data exists regarding diverse populations. However, the PREPARE model utilized fewer resources, while still increasing AD documentation within the EMR, through primary care clinics. This indicates it could be a viable option for communities and institutions with limited resources, but needs further implementation and dissemination to validate this interpretation. In conclusion, there is little research on ACP interventions in ethnically and racially diverse populations, but the available studies do demonstrate improved ACP engagement and documentation. More research on how to engage diverse patients in ACP is warranted for the aging and increasingly diverse patient population.

Implications for practice

Meeker and Jezewski (2004;2005) report that patients prefer to discuss advance care planning with their primary care provider, while they are in good health, and that providers should initiate the conversation. In addition to the above, family members often serve as

surrogates, but are typically ill prepared to be decision makers (Meeker & Jezewski, 2005). Therefore, as the research indicates, advance care planning is optimal patient care that should be happening sooner in one's life and preferably within the primary care setting.

ACP continues to be a challenge for patients, their families, practitioners, communities, and healthcare institutions. However, this literature review reveals that when ACP interventions target diverse patient populations, there is an increase in ACP engagement. Each article provides insight regarding the challenges of ACP and the need for more research regarding this topic. Healthcare systems and communities need to recognize the valuable implications of ACP engagement and how this favorably affects diverse populations. More training is needed for practitioners to assist with ACP and healthcare institutions need to employ more targeted ACP interventions for diverse groups that are culturally sensitive.

As the U.S. population continues to age and becomes more diverse, end-of-life-care planning will become more pertinent to the stakeholders of ACP engagement including patients, their families, the healthcare system and the communities they serve. Patients need assistance with ACP as they often are not aware of end-of-life-care planning or do not understand how to navigate ACP. This is especially true for diverse patient populations. There is ample opportunity for healthcare institutions to strategize culturally sensitive ACP programs for the patients and communities they serve, that is culturally appropriate. Compounding the lack of ACP engagement in diverse populations is a lack of practitioner preparedness to have these discussions and help guide patients through the ACP process which again is more prevalent for groups from different cultures.

Underserved populations are receiving more aggressive medical care even though

research indicates they prefer less aggressive treatment (Kelley, Wenger, & Sarkisian, 2010). Diverse patient groups are dying more often in the hospital, rather than at home or on hospice when compared to Caucasian groups. This phenomenon is not ethically sound care and there is a critical need for ACP education for diverse patients. The Patient Self-Determination Act clearly states ACP education should be standard care (ABA, 2013) and the Institute of Medicine has indicated that ACP education should be integrated into daily practice (IOM, 2014). Further, the American Nurses Association has provided a document that outlines the code of ethics for the nursing profession, entitled "Code of Ethics for Nurses with Interpretive Statements" (ANA.org, 2018). There are nine provisions and provision one specifically states "The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person" (ANA.org, 2018, page 1). This provision offers five guidelines and the fourth guideline is "The right to self-determination" (nursingworld.org). In their statement, they declare a patient has the right to "accept, refuse, or terminate treatment without deceit, undue influence, duress, coercion, or prejudice" (ANA.org, 2018, page 2). The health care system has a moral obligation to do so and nurse practitioners can be a primary driver in this effort.

It is imperative that healthcare practitioners and healthcare institutions prioritize end-of-life-care planning and employ effective interventions for diverse patient populations. Additionally, focus on staff development for ACP engagement that is culturally appropriate is also warranted as many practitioners do not feel prepared to have end-of-life-care discussions (Solis, Mancera, & Shen, 2018). Workflow for ACP engagement is a necessary priority for healthcare institutions as this is consistently recognized as a barrier for practitioners. With better integration of ACP into workflow patterns, there is more likelihood of patients and providers

having end-of-life-care discussions, and perhaps ACP could be considered a standard part of general healthcare maintenance.

References

American Bar Association (2013). Law for older Americans. Retrieved from https://www.americanbar.org/groups/public_education/resources/law_issures_for_consumers/patient_self-_determination_act/

Bullock, K. (2011). Influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care, 7,* 83-98. Doi: 10.1080/15524256.2011.548048

Bonner, G.J., Wang, E., Wilkie, D.J., Ferrans, C.E., Dancy, B., & Watkins, Y.J. (2014). Advance care treatment plan (ACT-Plan) for African American family caregivers: A pilot study. *Dementia (London), 13(1),* 1-17. doi:10.1177/1471301212449408

Hong, M., Yi, E., Johnson, K.J., & Adamek, M. E. (2018). Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: A systematic review of the current literature. *Journal of Immigrant and Minority Health, 20,* 1277-1287. doi:10.1007/s10903-017-0670-9

Huang, C. S., Crowther, M., Allen, R. S., DeCoster, J., Kim, G., Azuero, C., Ang, X., & Kvale, E. (2016). A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. *Journal of Palliative Medicine, 19(2),* 164-173. doi: 10.1089/jpm.2015.0334

Institute of Medicine (2014). Dying in American: 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

Johns Hopkins Hospital/The Johns Hopkins University (2012). Research evidence appraisal tool.

In *S. L. Dearholt & D. Dang. (Eds.). Johns Hopkins nursing evidence-based practice: Model and guidelines* (2nd ed., pp. 237-240). Indianapolis, IN: Sigma Theta Tau Internal Honor Society of Nursing

Kelley, A.S., Wenger, N.S., & Sarkisian, C.A. (2010). Opiniones: End-of-life care preferences for older Latinos. *Journal of American Geriatrics Society, 58,* 1109-1116.

Kulkarni, S.P., Karliner, L.S., Auerbach, A.D., & Perez-Stable, E.J. (2011). Physician use of advance care planning discussions in a diverse hospitalized population. *Journal of Immigrant Minority Health, 13,* 620-624. doi: 10.1007/s10903-010-9361-5

National Consensus Project for Quality Palliative Care (2018). Clinical practice guidelines for quality palliative care (4th edition). Retrieved from https://www.nationalcoalitionhpc.org/ncp/

Nedjat-Haiem, F.R., Carrion, I.V., Gonzalez, K., Quintana, A., Ell, K., O'Connell, M., Thompson, B., & Mishra, S.I.(2017). Implementing an advance care planning intervention in community settings with older Latinos: A feasibility study. *Journal of Palliative Medicine, 20,* 984-993. doi: 10.1089/jpm.2016.0504

Ortman, J.M., Velkoff, V.A., & Hogan, H. (2014). An aging nation: The older population in the United States. Retrieved from Https://www.census.gov/prod/2014pubs/p25-1140.pdf

Pecanac, K.E., Repenshek, M. F., Tennenbaum, D. & Hammes, B. J. (2014). Respecting choices and advance directives in a diverse community. *Journal of Palliative Medicine, 17(3),* 282-287. doi: 10.1089/jpm.2013.0047

Reuters (2017). Over one third of U.S. adults have advanced medical directives. Retrieved May

9, 2019 https://www.reuters.com/article/us-health-usa-advance-directives/over-one-third-of-u-s-adults-have-advanced-medical-directives-idUSKBN19W2NO

Rao, J.K., Anderson, L.A., Feng-Chang, L., & Laux, J.P. (2014). Completion of advance directives among U.S. consumers. *American Journal of Preventive Medicine 46(1),* 65-70. doi: http://dx.doi.org/10/1016/j.amepre.2013.09.008

Song, M., Ward, S.E., Lin, F., Hamilton, J.B., Hanson, L.C., Hladik, G.A., & Fine, J.P. (2016). Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. *Journal of Palliative Medicine, 19*(2), 134-141. doi: 10.1089/jpm.2015.0232

Solis, G.R., Mancera, B.M., & Johnson Shen, M. (2018). Strategies used to facilitate the discussion of advance care planning with older adults in primary care settings: A literature review. *Journal of the American Association of Nurse Practitioners, 30,* 270-279. doi: 10.1097/JXX000000000000025

Sudore, R.L., Schillinger, D., Katen, M.T., Shi, Y., Boscardin, W.J., Osua, S., & Barnes, D.E. (2018). Engaging diverse English- and Spanish-speaking older adults in advance care planning. *JAMA Internal Medicine, 178*(12), 1616-1625. doi: 10.1001/jamainternmed.2018.4657

Sudore, R. L., Boscardin, J., Feuz, M. A., McMahan, R. D., Katen, M. T., & Barnes, D. E. (2017). Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans. *JAMA Internal Medicine, 177(8),* 1102-1109. doi: 10.1001/jamainternmed.2017.1607

Sudore, R. L., Knight, S. J., McMahan, R. D., Feuz, M., Farrell, D., Miao, Y., & Barnes, D.E. (2014). A novel website to prepare diverse older adults for decision making and advance care planning: A pilot study. *Journal of Pain and Symptom Management, 47(4),* 674-686.

Sun, A., Bui, Q., Tsoh, J., Gildengorin, G., Chan, J., Cheng, J., Lai, K., Stephen, M., & Nguyen, T. (2017). Efficacy of a church-based, culturally tailored program to promote completion of advance directives among Asian Americans. *Journal of Immigrant and Minority Health, 19(2),* 381-391. doi: 10.1007/s10903-016-0365-7

Wilson, K. S., Kottke, T. E., & Schettle, S. (2014). Honoring choices Minnesota: Preliminary data from a community-wide advance care planning model. *Journal of American Geriatric Society, 62,* 2420-2425. doi: 10.1111/jgs.13136

Zapata, C., Lum, H.D., Wistar, E., Horton, C., & Sudore, R.L. (2018). Feasibility of a video-based advance care planning website to facilitate group visits among diverse adults from a safety-net health system. *Journal of Palliative Medicine, 21*(6), 853-857. doi: 10.1089/jpm.2017.0476

Appendix A

Research Evaluation Table

Citation	Conceptual Framework	Design/ Method	Sample/ Setting	Variables Studied and Their Definitions	Measurement	Data Analysis	Findings	Appraisal: Worth to Practice
Bonner, G.J., Wang, E., Wilkie, D.J., Ferrans, C.E., Dancy, B., & Watkins, Y.J. (2014). Advance care treatment plan (ACT-Plan) for African American family caregivers: A pilot study. *Dementia(London), 13(1),* 1-17. doi: 10.1177/1471301212449408	None stated	Pilot program: group-based education intervention. Two groups: ACT-Plan and attention control group. Subjects were not randomized	N=68, AA caregivers of relatives with dementia. Conducted in 5 adult day care centers in an urban setting.	Independent variable: ACT-Plan Dependent variable: knowledge about dementia, CPR, mechanical ventilation, tube feeing, and self-efficacy on decisions made.	Rate of AHD prior to respecting choices im-plementation 2005-2007	Descriptive statistics including means, frequencies, and standard deviations were utilized	ACT-Plan group: Increase in knowledge of dementia and self-efficacy; decrease in comfort with knowledge of CPR, MV, and TF; decrease in the decision to use CPR, MV, and TF.	**Strengths:** High attrition rate **Limitations:** Pilot study, subjects were not randomized **Critical Appraisal Tool & Rating:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 2B
Huang, C.H.S., Crowther, M., Allen, R.S., DeCoster, J.,	None stated	Mixed-method randomized controlled trial	N=30, African American, age 45 or older, no cognitive deficits	Dependent variables: Feasibility, know-ledge, intention to	Feasibility-program satisfaction survey; knowledge- 12	Quantitative analysis SPSS22.0. ANCOVAs intervention	Feasibility- more than 80% reported TAP intervention helped “very much”	**Strengths:** RCT focused on an underserved, diverse group.

Kim, G., Azuero, C., Ang, X., & Kvale, E. (2016). A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. *Journal of Palliative Medicine, 19(2),* 164-173. doi: 10.1089/jpm.2015.0334				complete an AD, Preference for an AD form In-dependent variable: TAP inter-vention	item scale; intention- single item question; Preference- single item question	knowledge, comparison of means for primary outcomes using paried sample t-tests	Knowledge- significant increase in intervention group Preference- both groups reported preference for adaptive AD form Intention- 100% increase	**Limitations:** small sample size, geographic specificity **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:1B
Nedjat-Haiem, F.R., Carrion, I.V., Gonzalez, K., Quintana, A., Ell, K., O'Connell, M., Thompson, B., & Mishra, S.I. (2017). Implementing an advance care planning intervention in community settings with	None stated.	Prospective, pretest/post-test, two group, randomized, community-based pilot.	N=74, >50, living in Southern New Mexico, having one more chronic diseases, Hispanic/Latino. Subjects were excluded if there was any possibility of limited cognitive functioning	Independent variables: ACP-I plan and usual care. Dependent variables: Satisfaction and feasibility of ACP-I	Pre/post-test surveys, Qualitative interviews	Mixed quantitative and qualitative methods utilized. "measures of feasibility were calculated." Satisfaction was measured by "acceptance of and retention in the program." Qualitative interviews were reviewed for	ACP-I was deemed feasible and helpful.	**Strengths:** Randomization of subjects to intervention and usual care. Good sample size for this type of study. **Limitations:** Convenience sampling, no pre-ACP knowledge assessment. **Critical appraisal tool:**

older Latinos: A feasibility study, *Journal of Palliative Care, 20*(9), 984-993. doi: 10.1089/jpm. 2016.0504						recurrent themes. .		John Hopkins nursing evidence-based practice research evidence appraisal tool:1B
Pecanac, K.E., Repenshek, M.F., Tennenbaum, D., & Hammes, B.J. (2014). Respecting choices and advance directives in a diverse community. *Journal of Palliative Medicine, 17(3),* 282-287. doi: 10. 1089/jpm. *of Palliative Medicine, 17(3),* 282-287. doi: 10. 1089/jpm.	None stated.	Retrospective chart review	N=732, decedents from 2005-2010, in 300 bed Midwestern metropolitan hospital.	Independent Variable: Respecting choices program Dependent Variable: Completion of AHD after respecting choices training	Rate of AHD prior to respecting choices im-plementation 2005-2007 rate of AHD after implement-tation of respecting choics 2008-2010.	Stata's TEFFECTS program was utilized to determine treatment effect of Respecting Choices	Significant increase in AHD in diverse groups after implement-tation of respecting choices 25.8%-38.4 no significant change for whites	**Strengths:** Retro-spective design **Limitations:** Selection bias, Other influences besides respecting choices **Critical Appraisal Tool & Rating:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 2B
Song, M., Ward, S.E., Lin, F., Hamilton, J.B., Hanson,	None stated.	A secondary data analysis of an RCT examining an ACP intervention	N= 420 participants with 210 surrogate dyads recruited from 20 dialysis centers	Independent variable: SPIRIT ACP intervention	Outcomes were compared for African Americans versus whites	Descriptive statistics were used to summarize participant	SPIRIT had a significant impact on African Americans for dyad congruence,	**Strengths:** based on an RCT, large sample size

L.C., Hladik, G.A., & Fine, J.P. (2016). Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. *Journal of Palliative Medicine*, *19*(2), 134-142. doi: 10.1089/jpm.2015.0232		(SPIRIT) versus usual care.		Dependent variable: dyad congruence on goals of care, surrogate decision making confidence, composite of the two, patient decisional conflict, surrogate bereavement outcomes		characteristics, *x2* and *t* were preformed to compare group difference within race and to compare African Americans with whites in baseline characteristics	surrogate decision-making confidence, and the composite-post intervention, and reducing bereavement depressive symptoms. It did not have a significant effect on the above for whites.	**Limitations:** exploratory analytic approach, as the original study was not designed to assess effects of race on SPIRIT, original study was done in one specific region of the U.S. and may not be applicable to other areas **Critical Appraisal Tool & Rating:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 1B
Sudore, R.L., Knight, S.J., McMahan, R.D., Feuz, M., Farrell, D., Miao, Y., & Barnes, D.E. (2014). A novel website to prepare diverse older adults for decision making and advance care planning: A	Social Cognitive Theory, Interpersonal Communication Competence Model, Behavior Change Theory	Pilot test of the PREPARE website for feasibility and ACP engagement	N=43, recruited from 3 low-income senior centers in San Francisco, English speaking only, 65% were non-white	Independent variable: PREPARE website Dependent variable: engagement in ACP	ACP engagement was measured with the ACP Engagement Survey.	Behavior Change Process Measures increased (Likert scores 3.1-3.7), significant decrease in precontemplation	Change from baseline to 1 week later (after exposure to PREPARE) were assessed with Wilcoxon signed rank sum test for continuous variables and McNemar's test for dichotomous variables	**Strengths:** PREPARE was rated as easy to use by diverse older adults **Limitations:** small sample, convenience sampling, tested in one region of the U.S., no control group **Critical Appraisal Tool & Rating:**

pilot study. *Journal of Pain and Symptom Management, 47(4),* 674-686.								John Hopkins nursing evidence-based practice research evidence appraisal tool: 2B
Sudore, R.L., Boscardin, J., Feuz, M.A., McMahan, R.D., Katen, M.T., & Barnes, D.E. (2017). Effect of the PREPARE website versus an easy-to-read advance directive on advance care planning documentation and engagement among veterans. *JAMA, 177(8),* 1102-1109. doi: 10.1001/jamainternmed.2017.1607	None stated- "previously published."	Single-blinded, parallel-group, randomized comparative Effectiveness Trial	N=414 recruited from VA Established in primary care as measured by 2 clinic visits in past year 2 chronic illnesses Exclusion criteria dementia, cognitive impairment, blindness, delirium, psychosis, active drug or ETOH abuse, plans of leaving town within 3 months, inability to answer informed consent teach-back questions within 3 attempts, no phone	Independent variable: Easy to read AD and PREPARE Dependent variable: New ACP docu-mentation at 9 months	New ACP documentation in EMR at 9 months after study enrollment Secondary outcomes: Validated, patient-reported ACP engagement Survey at 1 week, 3 months, and 6 months	Participant characteristics Fisher exact tests Intention to treat analysis using SAS stat software Mixed-effects logistic and linear regression with fixed effects	ACP documentation Higher in PREPARE plus AD group with p value of .04.	**Strengths:** RCT **Limitations:** Only 9% were women PREPARE must be seen on computer which may limit use at home Implications: Importance of facilitator for ACP documentation, ACP documents written at 12th grade level are less effective than ongoing education by health care professional **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:1A

Sudore, R.L., Schillinger, D., Katen, M.T., Shi, Y., Boscardin, W.J., Osua, S., & Barnes, D.E. (2018). Engaging diverse English-and Spanish-speaking older adults in advance care planning. *JAMA Internal Medicine, 178(12),* 1616-1625. doi: 10.1001/jamainternmed.2018.4657	None stated.	Randomized control trial	N=986 participants, limited health literacy, and 45.1% were Spanish speaking, recruited from 4 safety-net, primary care clinics in San Francisco	Independent variables: PREPARE plus and easy-to-read advance directive Dependent variables: New ACP documentation and ACP engagement	New ACP documentation in the medical record at 15 months, post-intervention. ACP Engagement Survey was utilized to measure ACP engagement of participants at 1 week, 3 months, 6 months, and 12 months	Documentation of ACP: mixed-effects logistic regression with fixed effects for time, group, and group-by-time interaction	ACP documentation was higher in the PREPARE group. An increase in behavior change and action scores in the PREPARE group for both English and Spanish speaking participants.	**Strengths:** RCT, large diverse sample size **Limitations:** Study conducted only in San Francisco, limiting generalizability. Participants could not be blinded, staff support could have also influenced ACP documentation. **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:1A
Sun, A., Bui, Q., Tsoh, J., Gildengorin, G., Chan, J., Cheng,J., Lai, K., Stephen, M., & Nguyen, T. (2017). Efficacy of a church-based, culturally tailored program to promote	Theory of Reasoned Action	Single group pilot study	N=174, self-identified as Chinese or Vietnamese, age 35 years or older.	Independent variable: two 2-hour group education sessions about advance directives. Session 1-endorsement of AD by a church leader, explanation of AD by a physician. Session 2-	Surveys were conducted pre-intervention and post- intervention immediately after and at 3 months.	SAS version 9.3. descriptive statistics including means, standard deviations and percentages-both separately for Chinese and Vietnamese and total sample	Significant increase in AD-related knowledge, intentions, and supportive beliefs about AD. 71.8% AD completion and 25% had a proxy conversation	**Strengths:** Culturally targeted intervention for AD completion shown to be effective. Large sample size. **Limitations:** No control group, convenience sampling. **Critical appraisal tool:**

completion of advance directives among Asian Americans. *Journal of Immigrant and Minority Health, 19(2),* 381-391. doi: 10.1007/s10903-016-0365-7				step-by-step instruction on completing an AD Dependent variable: AD-related knowledge, beliefs, attitudes, and intentions; AD completion, and conversation with a healthcare proxy				John Hopkins nursing evidence-based practice research evidence appraisal tool: 3B
Wilson, K.S., Kottke, T.E., & Schettle, S. (2014). Honoring choices Minnesota: Preliminary data from a community-wide advance care planning model. *Journal of American Geriatric Society, 62,* 2420-2425. doi:	None stated.	Pilot project	8 large health care systems in a major metropolitan area	Independent variable: Honoring Choices Minnesota Dependent variable: ACP document-tation	Self-reported data from each institution regarding ACP documentation	None stated.	27,000 individuals visited the website, the HCD form was downloaded 2200 times, two smallest healthcare systems had the highest rates of inpatient HCDs.	**Strengths:** Intervention was implemented in several health systems **Limitations:** pilot study with no control group, self- reported data from institutions **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 3C

10.1111/jgs.13136 Zapata, C., Lum, H.D., Wistar, E., Horton, C., & Sudore, R.L. (2018). Feasibility of a video-based advance care planning website to facilitate groups visits among diverse adults from a safety-net health system. *Journal of Palliative Medicine, 21(6),* 853-857. doi: 10.1089/jpm.2017.0476	None stated.	Feasibility pilot	N=22, greater than or equal to 50 years of age, two more chronic disease. Group visits (GV) conducted in two primary care clinics in Northern California	Independent variable: prepareforyourcare.org video presented in a GV setting Dependent variable: ACP knowledge, surrogate designation, completed AD	Pre and post-multiple-choice questionnaire, ACP Engagement Survey	Intercooled Stata, version 13. Percentages or means were calculated and compared using Fisher's exact tests or t-tests.	Surrogate decision knowledge improved from 46% to 85%, surrogate designation increased 48% to 85%, AD completion 9% to 24%, significance for feasibility	**Strengths:** First study to only use a video for ACP education in a group setting- no provider facilitator. **Limitations:** No control group, small sample size **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 3B