

Alabama at Birmingham School of Nursing, Birmingham, AL.

Objectives

- Describe important thematic differences between patients and family caregivers concerning the discussion of religion and spirituality in serious illness conversations with providers.
- Describe implications for palliative care practice and research related to religion and spirituality in patient-provider discussions about treatment plans, values, and end-of-life preferences.

Original Research Background. Religion and spirituality (R/S) plays a critical role in how African-Americans (AAs) cope with end-of-life yet is often omitted in patient-provider communication.

Research Objectives. To identify potential ways to include R/S in discussions with providers about serious illness from the perspectives of 1) AA patients with advanced heart failure (HF) and 2) their family caregivers (FCGs).

Methods. Individual semi-structured interviews were conducted with AA persons with NYHA class IIIa/IV HF and their FCGs recruited from an outpatient HF clinic at a large tertiary care academic medical center. The patient and FCG were asked how to best include R/S in patient-provider discussions about treatment plans, values, and end-of-life preferences. Transcribed interviews were analyzed using constant comparative analysis.

Results. AA patients (n=15) had a mean age of 62 years, were mostly male (60%), and most had >high school diploma/GED (87%). AA caregivers (n=14) had a mean age of 58 and 63% were patients' spouses/partners. Most caregivers were female (93%) with education >high school diploma/GED (93%). Most caregivers were unemployed (86%). All patients and FCGs were Protestant. Nearly all patients and FCGs reported that R/S is not discussed in clinical encounters. Concerning ideal R/S discussion integration in patient-provider communication, patients responded that either R/S should not be discussed at all or R/S should be discussed only if they initiated it. FCG interviews centered around three main contrasting themes concerning ideal integration of R/S into conversations: 1) provider should engage in faith practices with patients; 2) provider should be more willing to discuss R/S if the patient brings it up; and 3) providers' preferences should dictate R/S discussions.

Conclusion. There were key thematic differences between patients and FCGs concerning the discussion of R/S in serious illness conversations with providers.

Implications for Research, Policy, or Practice. Patient/FCG perspective differences on R/S should be considered in the design of end-of-life provider discussion interventions.

Partnering with African American Pastors and Healthcare Professionals to Develop Training Videos that Demonstrate Culturally Appropriate Physician Communication Principles and Methods (FR421C)



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Objectives

- Describe how to determine the cultural values and goals of their patients.
- Develop a training video with their partners.

Original Research Background. Culture significantly impacts the way people think of illness, suffering, and dying. Lack of understanding by clinicians of their patients' unique culture often results in miscommunication, lack of trust, frustration, and patients not receiving goal-concordant care.

Research Objectives. Use Community Based Participatory Research to develop and test the efficacy of training videos highlighting culturally appropriate communication methods for physicians caring for Rural Southern African Americans (RSAA) with serious illness. Phase 1: Determine how RSAA pastors and patients with a serious illness and their families prefer clinician communication. Phase 2: In partnership with RSAA pastors and healthcare providers, develop training videos, each of which demonstrates a culturally appropriate physician communication principle and method(s). Phase 3 (not reported): Following training with the videos, determine physicians' confidence in communicating with their RSAA patients and family in a culturally appropriate manner.

Methods. Phase 1: Two focus groups were conducted with RSAA: (a) Local pastors and (b) patients and caregivers. Questions focused on how they wanted physicians to communicate with and care for their loved ones. Data was analyzed using thematic analyses. Phase 2: Based on each Phase 1 theme, CAG members developed a scenario that they scripted and in which they acted, that was filmed by a RSAA filmmaker.

Results. Phase 1: Themes included maintaining hope despite life-limiting prognosis; focus on the family, not just the patient; importance of spirituality/religion; and the significant role of pastors. Phase 2: A series of scenarios were developed based on each emergent

theme. Videos included a cultural explanation of the need for such communication.

Conclusion. Partnering with RSAA pastors and healthcare providers resulted in the development of a series of training videos that focus on culturally respectful communication methods for clinicians caring for RSAs with serious illness.

Implications for Research, Policy, or Practice. Enhancing clinicians' knowledge of culturally appropriate communication has the potential to build trust and meet RSAA patients' goals of care.

Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial (FR421D)



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Objectives

- Describe the design and implementation of free, easy-to-use, patient facing advance care planning tools (www.prepareforyourcare.org), particularly for vulnerable and disenfranchised populations.
- Describe the comparative efficacy of an online advance care planning program called PREPARE (www.prepareforyourcare.org) plus an easy-to-read (5th-grade reading level) advance directive versus an advance directive alone on new advance care planning documentation and self-reported advance care planning engagement without additional clinician or system-level interventions.

Original Research Background. Advance care planning (ACP) improves value-aligned care; yet, it remains sub-optimal among diverse patient populations. To mitigate literacy, cultural, and language barriers, we created easy-to-read advance directives (ADs) and a patient-directed, online ACP program called PREPARE in English and Spanish.

Research Objectives. To compare the efficacy of PREPARE plus an easy-to-read AD (PREPARE arm) to an AD alone to increase ACP documentation and patient-reported engagement.

Methods. We conducted a comparative efficacy randomized trial from February 2014 to November 2017 in four San Francisco, safety-net, primary-care clinics among English- or Spanish-speaking adults age ≥ 55 years, with ≥ 2 chronic or serious illnesses. Participants

were randomized to the PREPARE arm or the AD alone. There were no clinician/system-level interventions. Staff were blinded for all follow-up assessments. The primary outcome was new ACP (i.e., legal forms and/or documented discussions) at 15 months. Patient-reported outcomes included ACP engagement at baseline; 1 week; and 3, 6, and 12 months using validated surveys. We used intention-to-treat, mixed-effects logistic and linear regression, controlling for time, health literacy and baseline ACP, clustering by physician, and stratifying by language.

Results. The mean (SD) age of 986 participants was 63.3 years (± 6.4); 39.7% had limited health literacy; and 45% were Spanish-speaking. No participant characteristic differed between arms; retention was 85.9%. Compared to the AD alone, PREPARE resulted in higher ACP documentation (adjusted 43% vs. 32%; $p < 0.001$) and higher self-reported increased ACP engagement (98.1% vs. 89.5%; $p < 0.001$). Results remained significant among English and Spanish speakers.

Conclusion. The patient-facing PREPARE program and an easy-to-read AD, without clinician/system-level interventions, increased ACP documentation and patient-reported engagement, with statistically higher gains for PREPARE for both English- and Spanish-speaking older adults.

Implications for Research, Policy, or Practice. These tools may mitigate literacy and language barriers to ACP, allow patients to begin planning on their own, and could substantially improve the process for diverse, English- and Spanish-speaking populations.

1:30–2:30 pm

Concurrent Sessions

The Practice of Palliative Medicine in Developing Countries—Part One (FR430)



Natalia Carafizi, MD MPH, Charity Foundation for Public Health, Chisinau, Moldova. Mohd Khilji, MD, S P Medical College, Bikaner, India. Atif Waqar, MBBS, Aga Khan University Hospital, Karachi, Pakistan.

Objectives

- Learn how physicians in specific countries provide palliative care to their patient populations often with limited resources.
- Recognize specific cultural and political challenges to developing palliative care clinical, educational and research programs.
- Describe roles of different health care providers practicing palliative care and how they meet the needs of their local populations.