Title:

End of Life in African American Older Adults: An Integrative Literature Review

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Session Title:

Rising Stars of Nursing Invited Posters - Group 2

Slot (superslotted):

RSG STR 2: Friday, September 26, 2014: 10:00 AM-10:30 AM

Slot (superslotted):

RSG STR 2: Friday, September 26, 2014: 11:45 AM-1:00 PM

Slot (superslotted):

RSG STR 2: Friday, September 26, 2014: 3:00 PM-3:30 PM

Keywords:

African American, end of life and older adults

References:

Allen, J. Y., Hilgeman, M. M., & Allen, R. S. (2011). Prospective end-of-life treatment decisions and perceived vulnerability: Future time left to live and memory self-efficacy. Aging & Mental Health, 15(1), 122-131. doi:10.1080/13607863.2010.505229 Allen, R. S., Allen, J. Y., Hilgeman, M. M., & DeCoster, J. (2008). End-of-life decision-making, decisional conflict, and enhanced information: Race effects. Journal of the American Geriatrics Society, 56(10), 1904-1909. doi:10.1111/j.1532-5415.2008.01929.x Anthony, J. S. (2007). Self-advocacy in health care decision-making among elderly African Americans. Journal of Cultural Diversity, 14(2), 88-95. Barnato, A. E., Anthony, D. L., Skinner, J., Gallagher, P. M., & Fisher, E. S. (2009). Racial and ethnic differences in preferences for end-of-life treatment. Journal of General Internal Medicine, 24(6), 695-701. Barnato, A. E., Chang, C. C., Saynina, O., & Garber, A. M. (2007). Influence of race on inpatient treatment intensity at the end of life. Journal of General Internal Medicine, 22(3), 338-345. Barrett, R. K. (2005). Dialogues in diversity: An invited series of papers, advance directives, DNRs, and end-of-life care for African Americans, Omega: Journal of Death & Dving, 52(3). 249-261. Barrett, R. K. (2006). Dialogues in diversity: An invited series of papers, advance directives, DNRs, and end-of-life care for African Americans. In K. Doka's (Ed.) OMEGA Journal of Death & Dying, 52(3), 2005-2006, Amityville, NY: Baywood Publishing Company, Inc., 249 - 261. Barrett, R. K. (2009). Sociocultural considerations: African Americans, grief, and loss. In Doka, K. J. & Tucci, A. S. (Eds.) Living with Grief: Diversity and End-of-Life Care. Washington, D.C.: Taylor & Francis Publishers, Inc., 83-96. Barrett, R. K. (2012). The African American call to gather: An enduring cultural tradition. The FORUM: Association for Death Education and Counseling, Inc., 38(1), 11 Bullock, K. (2006). Social work series. Promoting advance directives among African Americans: A faith-based model. Journal of Palliative Medicine, 9(1), 183-195. Bullock, K. (2011). The influence of culture on end-of-life decision making. Journal of Social Work in End-of-Life & Palliative Care, 7(1), 83-98. Bullock, K., Hall, J. K., & Leach, M. T. (2014). End-of-life care among older minorities. In Whitfield, K. E. & Baker, T. A. (Eds.), Handbook of minority aging (265-276). New York, New York: Springer Publishing Company. Campbell C. (2007). Keeping faith. Journal of Hospice & Palliative Care Nursing 9(1), 31-41. Campbell, C., Williams, I.C., & Orr, T. (2010). Factors that impact end-of-life decision making in African Americans with advanced cancer. The Journal of Hospice and Palliative Nursing, 12(4), 214-224. Conner, N. E., & Chase, S. K. (2014). Decisions and caregiving: End of life among Blacks from the perspective of informal caregivers and decision makers. American Journal of Hospice and Palliative Medicine, doi:10.1177/1049909114529013 Enguidanos, S., Kogan, A. C., Lorenz, K., & Taylor, G. (2011). Use of role model stories to overcome barriers to hospice among African Americans. Journal of Palliative Medicine, 14(2), 161-168. Fairfield, K. M., Murray, K. M., Wierman, H. R., Han, P. K., Hallen, S., Miesfeldt, S., . . . Earle, C. C. (2012). Disparities in hospice care among older women dying with ovarian

cancer. Gynecologic Oncology, 125(1), 14-18. Gardner, D. S., & Kramer, B. J. (2009). End-of-life concerns and care preferences: Congruence among terminally ill elders and their family caregivers. Omega: Journal of Death & Dying, 60(3), 273-297. doi:10.2190/OM.60.3.e Givens, J. L., Tjia, J., Zhou, C., Emanuel, E., & Ash, A. S. (2010). Racial and ethnic differences in hospice use among patients with heart failure. Archives of Internal Medicine, 170(5), 427-432. Haas, J. S., Earle, C. C., Orav, J. E., Brawarsky, P., Neville, B. A., Acevedo-Garcia, D., & Williams, D. R. (2007). Lower use of hospice by cancer patients who live in minority versus white areas. Journal of General Internal Medicine, 22(3), 396-399. Hanchate, A., Kronman, A. C., Young-Xu, Y., Ash, A. S., & Emanuel, E. (2009). Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites?. Archives of Internal Medicine, 169(5), 493-501. Hardy, D., Chan, W., Liu, C. C., Cormier, J. N., Xia, R., Bruera, E., & Du, X. L. (2012). Racial disparities in length of stay in hospice care by tumor stage in a large elderly cohort with non-small cell lung cancer. Palliative Medicine, 26(1), 61-71. Holley, A. P., Gorawara-Bhat, R., Dale, W., Hemmerich, J., & Cox-Hayley, D. (2009). Palliative access through care at home: Experiences with an urban, geriatric home palliative care program. Journal of the American Geriatrics Society, 57(10), 1925-1931. Hopp, F. P., Thornton, N., Martin, L., & Zalenski, R. (2012). Life disruption, life continuation: Contrasting themes in the lives of African American elders with advanced heart failure. Social Work in Health Care, 51(2), 149-172. Johnson, K. S., Elbert-Avila, K. I., & Tulsky, J. A. (2005). The influence of spiritual beliefs and practices on the treatment preferences of African Americans: A review of the literature. Journal of the American Geriatrics Society, 53(4), 711-719. Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2008). What explains racial differences in the use of advance directives and attitudes toward hospice care?. Journal of the American Geriatrics Society, 56(10), 1953-1958. Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2009). Racial differences in self-reported exposure to information about hospice care. Journal of Palliative Medicine, 12(10), 921-927. Kelley, A. S., Ettner, S. L., Morrison, R. S. Du, Quingling & Sarkisian, C. A. (2012). Disability and decline in physical function associated with hospital use at end of life. Journal of General Internal Medicine, 27(7): 794-800. doi:10.1007/s11606-012-2013-9 Lackan, N. A., Eschbach, K., Stimpson, J. P., Freeman, J. L., & Goodwin, J. S. (2009). Ethnic differences in in-hospital place of death among older adults in California: Effects of individual and contextual characteristics and medical resource supply. Medical Care, 47(2), 138-145. Lepore, M. J., Miller, S. C., & Gozalo, P. (2011). Hospice use among urban black and white U.S. nursing home decedents in 2006. Gerontologist, 51(2), 251-260. Melhado, L., & Bushy, A. (2011). Exploring uncertainty in advance care planning in African Americans: Does low health literacy influence decision-making preference at end of life. American Journal of Hospice & Palliative Medicine, 28(7), 495-500. National Institutes of Health. (2012). End of life. NIH Senior Health. Retrieved from http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html Morris, A. M., Billingsley, K. G., Hayanga, A. J., Matthews, B., Baldwin, L. M., & Birkmeyer, J. D. (2008). Residual treatment disparities after oncology referral for rectal cancer. Journal of the National Cancer Institute, 100(10), 738-744. O'Hare, A. M., Rodriguez, R. A., Hailpern, S. M., Larson, E. B., & Kurella Tamura, M. (2010). Regional variation in health care intensity and treatment practices for end-stage renal disease in older adults. JAMA, 304(2), 180-186. Ott, B. B. (2008). Views of African American nursing home residents about living wills. Geriatric Nursing, 29(2), 117-124. doi:10.1016/j.gerinurse.2007.05.001 Park, N. S., Carrion, I. V., Lee, B. S., Dobbs, D., Shin, H. J., & Becker, M. A. (2012). The role of race and ethnicity in predicting length of hospice care among older adults. Journal of Palliative Medicine, 15(2), 149-153. Patient Self-Determination Act of 1990. 101st Congress. H.R.4449. Retrieved from: http://thomas.loc.gov/cgibin/query/z?c101:H.R.4449.IH: Philips, L. R. & Reed, P. (2009). End-of-life caregiver's perspectives on their role: generative caregiving. The Gerontologist, 50(2), 204-214. doi: 10.1093/geront/gnp116 Schulz, R. & Hanusa, B. H. (1980). Applications of experimental social psychology to aging. Journal of Social Issues, 36, 30-47. SUPPORT Principal Investigators, (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). Journal of the American Medical Association, 274:1591-1598. Song, M. K., Donovan, H. S., Piraino, B. M., Choi, J., Bernardini, J., Verosky, D., & Ward, S. E. (2010). Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. Applied Nursing Research, 23(2), 65-72. Song, M. K., & Hanson, L. C. (2009). Relationships between psychosocial-spiritual well being and end-of-life preferences and values in African American dialysis patients. Journal of Pain & Symptom Management, 38(3), 372-380. Song, M. K., Ward, S. E., Happ, M. B., Piraino, B., Donovan, H. S., Shields, A. M., & Connolly, M. C. (2009). Randomized controlled trial of SPIRIT: An effective approach to preparing African-American dialysis patients and

families for end of life. Research in Nursing & Health, 32(3), 260-273. The Institute of Medicine (1997). Approaching death: improving care at the end of life. In M. J. Field & C. K. Cassel (Ed.), Retrieved from http://www.nap.edu/catalog.php?record_id=5801 The United States Census Bureau (2011). The Black population: 2010. Retrieved from

http://search.census.gov/search?utf8=%E2%9C%93&affiliate=census&guer Volker, D. L. (2005). Control and end-of-life care: Does ethnicity matter? American Journal of Hospice & Palliative Medicine, 22(6), 442-446. Volker, D. L., & Wu, H. L. (2011). Cancer patients' preferences for control at the end of life. Qualitative Health Research, 21(12), 1618-1631. Waters, C. M. (2001). Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. Qualitative Health Research, 11(3), 385-398. doi:10.1177/104973201129119172 Weiner, J. M. & Tilly, J. (2003). End-of-life care in the United States: Policy issues and model programs of integrated care. International Journal of Integrated Care 3: 1-11. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1483949/ Whitfield, K.E., Allaire, J., Belue, R., & Edwards, C.L. (2008). Are comparisons the answer to understanding behavioral aspects of aging in racial and ethnic groups? Journals of Gerontology: Psychological Sciences, 63B(5), 301-308. Winter, L., & Parker, B. (2007). Current health and preferences for lifeprolonging treatments: An application of prospect theory to end-of-life decision-making. Social Science & Medicine, 65(8), 1695-1707. doi:10.1016/j.socscimed.2007.06.012 Winter, L., Dennis, M. P., & Parker, B. (2007). Religiosity and preferences for life-prolonging medical treatments in African-American and White elders: A mediation study. Omega: Journal of Death & Dying, 56(3), 273-288. doi:10.2190/OM.56.3.d Zheng, N. T., Mukamel, D. B., Caprio, T., Cai, S., & Temkin-Greener, H. (2011). Racial disparities in inhospital death and hospice use among nursing home residents at the end of life. Medical Care, 49(11), 992-998.

Learning Activity:

LEARNI NG OBJECTI VES	EXPAN DED CONTE NT OUTLIN E	TIME ALLOT TED	FACULTY/SPE AKER	TEACHING/LEA RNING METHOD	EVALUATION/FE EDBACK
Example	Example	Example	Example	Example	Example
selected definition of the term,	Definitio ns of "curricul um" Course of study Arrange ments of instructio nal materials The subject matter that is taught	20 minutes	Name, Credentials	Lecture PowerPoint presentation Participant feedback	Group discussion: What does cultural training mean to you?

	Cultural "training" Planned engagem ent of learners				
Discuss common research findings in end-of-life decision making in African American older adults.		10 minutes	·	Face-to-face discussion	Discussion feedback and input/suggestions
Identify key factors that influence end-of-life decision making in African	salient influenci	10 minutes	Karen O. Moss, MSN, RN, CNL	Face-to-face discussion	Discussion feedback and input/suggestions

American older adults.	life decisions in this		
	populatio n? How		
	are these factors		
	related?		

\Abstract Text:

Background: End-of-life care in the United States is described as deficient and fragmented. Minority populations engage in end-of-life planning less frequently than Caucasians. African Americans represent the second largest minority group in the United States with its older adult population projected to increase by 114% by 2030. The Patient-Self Determination Act of 1990 requires Medicare and Medicaid funded healthcare organizations to empower patients to refuse or accept medical care and execute advance directives. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) confirmed substantial shortcomings of healthcare for seriously ill patients near the end of life. From this study came the Institute of Medicine's report Approaching Death: Improving Care at the End of Life, which further demonstrated the need for evidence-based end-of-life care models. End-of-life care is the broad term used to describe the attention and support given during the period leading to death. Advance directives are a mechanism to safeguard control over decision making when one can no longer express preferences for end-of-life care.

Methods: Literature searches were conducted using the following databases: CINAHL, Cochrane Library, Ovid MEDLINE, Pub Med, Psych Info, Web of Science and ancestry searches. Keywords used were: African American, Blacks, end of life and older adults. Articles searched were published between 2007 and 2014. Studies were included based on the following criteria: (a) included African Americans, (b) participants were 60 years of age or older, (c) the issue of end of life was addressed, (d) research-based, and (e) published in the English language. Twenty-eight articles met these criteria.

Findings: African Americans use hospice and prepare advanced directives less often as compared to Caucasians or other races. African American older adults, in general, tend not to prepare advance directives as the focus is often on interment preparation versus symptom management care trajectory. African American decedents generally received more life-sustaining interventions than non-Blacks during hospitalization near the end of life. Among the many factors that may contribute to African American older adult end-of-life decision making, the following were most salient: (1) individual and familial belief systems, (2) culture and socialization, (3) religion/spirituality, and (4) past events in history that have led to mistrust of the United States healthcare system. The majority of research conducted on this topic was done so in the oncology, renal, and cardiology populations. African American older adults place significant emphasis on family involvement in healthcare decision making.

Conclusions: Confluences of multiple factors contribute to African American end-of-life decision making. Based on this review, further research is needed on end-of-life decision making for African American older adults with an emphasis on strategies to improve this experience for older adults with cognitive impairment such as dementia using their family caregivers. A better understanding of end-of-life decision making processes in this population is needed for the development of culturally tailored end-of-life educational interventions to meet the specific needs of patients and families, improving end-of-life care and subsequently quality of life for all involved.