Cultural Aspects of End of Life Advance Care Planning for African Americans: An Ethnonursing Study

John Collins

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CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE PLANNING FOR AFRICAN AMERICANS: AN ETHNONURSING STUDY

A Dissertation
Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for the degree of Doctor of Philosophy

By

John W Collins

August 2019
CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE PLANNING FOR
AFRICAN AMERICANS: AN ETHNONURSING STUDY

By

John W Collins

Approved May 8, 2019

Rick Zoucha, PhD, PMHCNS-BC, CTN-A, FAAN
Professor and Chair of Advanced Role and PhD Programs
Duquesne University
(Committee Chair)

Sandra J. Mixer, PhD, RN, CTN-A
Associate Professor of Nursing
University of Tennessee-Knoxville
(Committee Member)

Joan Such Lockhart, PhD, RN, CNE, ANEF, FAAN
Professor of Nursing
Duquesne University
(Committee Member)

Mary Ellen Glasgow
Dean, School of Nursing
Professor of Nursing
Duquesne University
ABSTRACT

CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE PLANNING FOR AFRICAN AMERICANS: AN ETHNONURSING STUDY

By

John W Collins

August 2019

Dissertation supervised by Professor Rick Zoucha

Introduction: Advance directive completion rates among the general population are low. Studies report even lower completion rates among African Americans are impacted by demographic variables, cultural distinctives related to patient autonomy, mistrust of the healthcare system, low health literacy, strong spiritual beliefs, desire for aggressive interventions, importance of family-communal decision making, and presence of comorbidities. End of Life (EOL) advance care planning (ACP) promotes patient and family centered care. The purpose of this study was to identify culturally based meanings, expressions, and traditions of EOL ACP and decision making among African Americans, to better understand and provide culturally congruent nursing care to this population.
Methodology: Leininger’s Culture Care Theory and Ethnonursing Method guided the study. A convenience sample of 21 informants from the Midwestern U.S. were interviewed in community settings. Data analysis was guided using Leininger’s Phases of Ethnonursing Data Analysis for Qualitative Data.

Results: Data revealed three themes which impact EOL decision making: (a) Faith in God and belief in life after death (b) A strong matriarchal structure of African American families, and (c) Fear of talking about death and mistrust of the U.S. healthcare system.

Discussion: African American culture, beliefs, and traditions influence EOL ACP and practices, and must be considered in provision of culturally congruent care.

Keywords: end of life, advance directive, advance care planning, culture, cultural values and beliefs, ethnonursing, African American
DEDICATION

I would like to dedicate this work to the men and women who opened their hearts, lives, and families to share with me their values, beliefs and traditions that are the data of this study. I honor their willingness to share personal and sometimes difficult experiences so that I might complete this study, but ultimately their sharing contributes to the body of nursing knowledge so that we all might learn how to better care for them and their loved ones in End of Life situations.
ACKNOWLEDGEMENT

I want to thank my committee chair, Dr. Rick Zoucha, and committee members, Dr. Joan Such Lockhart, and Dr. Sandra Mixer for their excellent guidance of my research design, process and implementation. I also want to acknowledge my wife, Debra and family and thank them for their support throughout the years of completing this program. Most importantly, I thank my Lord and Savior Jesus Christ for his love, care, and strength to do this work.
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<tr>
<td>Advance Care Planning</td>
<td>ACP</td>
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<td>African American</td>
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<td>Culture Care Theory, or Theory of Culture Care Diversity and Universality</td>
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<td>Durable Power of Attorney for Healthcare</td>
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<td>Integrative Review</td>
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<td>Living Will</td>
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<td>Patient Self Determination Act</td>
<td>PSDA</td>
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<td>Quality Assessment Tool for Studies of Diverse Design</td>
<td>QATSDD</td>
</tr>
<tr>
<td>Randomized Control Trial</td>
<td>RCT</td>
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<tr>
<td>Risk Ratio</td>
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<td>White American</td>
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Integrative Review of Literature

End of life (EOL) care that honors the wishes of individuals and families is a complex issue with few easy answers. According to Koss and Baker, “advance care planning is a process through which competent adults can discuss their healthcare goals and communicate their preferences about life-sustaining treatment in the event they are ever unable to make medical decisions for themselves” (2017, p. 2). When advance care planning (ACP) is not completed, healthcare decision making for incapacitated loved ones can be stressful and difficult, resulting in family members often choosing life-prolonging interventions including extensive and invasive medical procedures (Hendricks Sloan et al., 2016; Sanders, Robinson, & Block, 2016).

This dilemma has long been a topic of conversation by ethicists, politicians, healthcare professionals, and individual families. High profile bioethics cases like Karen Ann Quinlan in 1976, Nancy Cruzan in 1990, and more recently Terri Schiavo in 2005 have prompted public discourse about surrogate decision making, medical intervention to maintain artificial respiration and circulation, or allowing natural death to occur (Annas, 2005). While public conversation waxes and wanes relative to national and global awareness of EOL care issues, healthcare decision making by a surrogate is difficult without prior ACP as a guide for EOL care. The above-mentioned cases are more complex than the singular issue of EOL ACP however the Quinlan and Cruzan cases and the ensuing public discourse were the impetus of the Patient Self Determination Act (PSDA) of 1991 (Congress, 1990).

Passage of the Patient Self Determination Act sought to encourage creation of Advance Directives (AD), bring about nationwide EOL legislative uniformity, and when in place requires adherence to ADs by healthcare providers (Breu, 2012). To facilitate AD creation, the PSDA requires health care facilities receiving Medicare and Medicaid funding to educate and offer
patients the option of creating an AD with assistance from facility staff. PSDA requirements include: (a) clinical facilities maintain written institutional policies requiring clients be asked about ADs, (b) facilities educate clinical staff about the value of AD completion, (c) require clinical staff to ask and document if clients have an AD, (d) provide clients with written educational information about ADs, and (e) notify clients in writing that provision of healthcare is not contingent upon AD completion (Institute of Medicine of the National Academies, 2015).

ADs, also referred to as Living Wills (LW) or Durable Power of Attorney for Healthcare (DPAHC), are documents describing individuals’ EOL care preferences (Institute of Medicine of the National Academies, 2015). ADs provide family members and medical professionals with information needed to honor healthcare treatment choices in case of future incapacity, and may include designation of a surrogate(s) to make healthcare decisions on behalf of the patient. Surrogates are typically named in DPAHC documents (Ko & Lee, 2014; Shapiro, 2015; United States Government Accountability Office, 2015).

Background

Personal EOL care documents had their genesis in the United States (US) in the late 1960s when introduced by the Euthanasia Society of America (Breu, 2012). Medical advances of recent decades and new life-sustaining procedures have blurred the distinction between life and death (Morhaim & Pollack, 2013; U.S. Department of Health and Human Services, 2008). While seemingly possible to keep a body alive indefinitely, concern for artificially extending respiration and circulation beyond natural life is an issue that causes personal, spiritual, and financial stress for family members when patients have not recorded their EOL care preferences (Carr, 2012; Hendricks Sloan et al., 2016). ADs eliminate many stressors by outlining the extent of medical interventions desired by patients, while accommodating families’ peace of mind.
knowing they are respecting the wishes of their loved ones. ADs also provide direction for healthcare providers (Campbell, Edwards, Ward, & Weatherby, 2007). Research indicates patients who participate in ACP and complete ADs “are more likely to receive less aggressive, more goal-concordant care, more and earlier hospice care, and to experience greater satisfaction with care” (Breu, 2012; Sanders et al., 2016, p. 202). Failure to make EOL healthcare wishes known can result in unwanted treatments, added decisional and financial stress on families, and increased health care costs for individuals, families and the healthcare system (Institute of Medicine of the National Academies, 2015; Ko & Lee, 2014).

The rate of EOL ACP, measured by AD completions among the general US adult population, is lower than desired with rates among minorities being much lower. The largest disparity in AD rates is between African Americans (AA) at 17-24%, and White Americans (WA) at 30-45% (Garrido, Harrington, & Prigerson, 2014; Huang, Neuhaus, & Chiong, 2016; Rao, Anderson, Lin, & Laux, 2014). This disparity has negative personal, social, and financial implications for AA individuals and families. Research suggests that multiple factors, such as family dynamics as well as interactions among patients, family members, and healthcare providers impact EOL decision making among AAs (Smith-Howell, Hickman, Meghani, Perkins, & Rawl, 2016). Similarly, hospice and palliative care as ACP options are used less by AAs than WAs (Frahm, Brown, & Hyer, 2015; Lovell & Yates, 2014).

Studies report ACP reduces stress and is associated with improved quality of life for family members, caregivers and surrogates (Campbell et al., 2007; Koss & Baker, 2017; Sanders et al., 2016). Unfortunately, interventions to help AAs embrace ACP and that do not conflict with their cultural beliefs and traditions, still elude the healthcare community (Rhodes, Batchelor, Lee, & Halm, 2015). A premise of the PSDA legislation is that patients value
personal autonomy and the right to decide the extent and types of interventional care received at EOL. Studies document ACP for EOL may not be congruent with AA cultural beliefs and traditions, thereby making the mandated requirements of the PSDA for healthcare institutions culturally insensitive to the AA community (Giger, Davidhizar, & Fordham, 2006; Huang, Neuhaus, et al., 2016; Volker, 2005; Wicher & Meeker, 2012). Understanding of this cultural distinctive is foundational to this Integrative Review (IR), which seeks to understand underlying beliefs, traditions, and cultural influences that impact EOL care planning among AAs.

**Study Purpose**

Nurses need to gain understanding of EOL values, beliefs and traditions to improve care of AAs facing this inevitable time of life. The purpose of this IR is to synthesize current nursing knowledge about EOL and ACP values, beliefs and traditions among AAs.

**Methodology**

**Design**

Methodological strategies set forth by Whittemore and Knafl (2005) guided the IR, the broadest method of conducting a review of literature including both experimental and non-experimental empirical studies, and theoretical literature to gain comprehensive understanding of the current state of knowledge. This approach is intended to increase scientific rigor and define the process of including diverse methodological studies from a broad research spectrum. Steps of this multi-stage IR process include: (a) problem identification, (b) literature search collection methods including identification of search terms and appropriate computerized databases, (c) data evaluation (d) data analysis, and (e) presentation of results (Whittemore & Knafl, 2005).
Setting and Sample Selection

To assess publications related to EOL and ACP, published research articles were identified using electronic databases CINAHL, PubMed, and Google Scholar, with the assistance of a health sciences librarian. Search terms included terminal care, advance care planning, culture, religion, ethnology, and ethnic groups. Articles incorporated in the review included those identified and retrieved using the search engine data bases, as well as other articles suggested by the search engines during the review process. Reference lists of selected articles were gleaned to identify earlier research and authors whose work was cited frequently. Three authors appeared repeatedly (Johnson, Kuchibhatla, & Tulsky, 2008; Melhado & Bushy, 2011; Torke, Garas, Sexson, & Branch, 2005), and were included in this review to understand earlier research surrounding ADs. Another five articles that had not been identified by the search engines but fit inclusion criteria thus were also included. Criteria for inclusion were studies that addressed: (1) research purposed to identify EOL care planning issues across all cultures (2) AD completion rates and barriers to completions per demographic factors, (3) cultural perspectives of ACP at EOL, and (4) study participants were adult residents of the US; within those parameters only articles printed in English were reviewed. Articles were excluded if they were from a pediatric perspective, focused only on disease specific populations, or if data gathered was from a nursing or healthcare provider perspective versus patient/family perspective. Articles retrieved were published between 2005 and 2016. Due to passage of the PSDA of 1991, research about the initiation and completion of ADs was completed in those years following enactment of the statute. Therefore, several foundational articles from the mid-2000s were included in the IR to provide background and context of AD and ACP education, promotion, and completion.
Figure 1 (Moher, Liberati, Tetzlaff, & Altman, 2009) illustrates the process used to identify and review articles. Initially, 776 articles were identified via the search engines using the search terms, and another eight ancestry articles were identified from the included studies. Of the 784 articles screened, 733 were excluded as not meeting the inclusion criteria. Further review eliminated 27 more that did not address AA cultural perspectives of ACP. Government reports were included in the IR because they provided foundational AD knowledge, background to enactment of the PSDA, and data of prevalence of ADs, ACP, and EOL documentation.

Some of the articles returned by the search engines were expert opinion, as well as reports of ACP and AD prevalence and government reports about implementation of the PSDA; these were identified and used as reference and foundational information for problem identification. Twenty-four studies that met the inclusion criteria as research were incorporated in this IR. Table 1 provides a detailed summary of the sample studies.

Sample Description

Of the 24 studies included in this review, 16 were qualitative, six were Reviews of Literature of qualitative and quantitative studies, one was a mixed-method study, and one was purely quantitative. Among qualitative studies, 11 were descriptive with convenience and purposive sampling, while three used a longitudinal prospective design, and two utilized large national secondary data sets. The mixed-method study had a descriptive piece and a randomized control trial (RCT) as the quantitative piece. The purely quantitative study was a RCT utilizing a face to face teaching intervention, versus simply provision of materials with no face to face component.
**Outcome Measures**

Each of the 24 research studies was independently assessed for quality using the Quality Assessment Tool for Studies of Diverse Designs (QATSDD) tool (Sirriyeh, Lawton, Gardner, & Armitage, 2012), an interdisciplinary quality assessment tool that is particularly useful to health services researchers in psychology, sociology and nursing. It was developed to assess quality of both quantitative and qualitative studies using a single tool, thereby removing much of the subjectivity of comparing studies that have been evaluated using separate (qualitative or quantitative) evaluative tools. The QATSDD consists of 16-items/questions with 14 of the 16 items applicable to qualitative research, 14 of the 16 items applicable to quantitative research, and all 16 items applicable to mixed-methods research. The result of the evaluation is a numeric score (% of maximum score possible) whereby studies of diverse designs are compared. Quality scores are recorded in Table 1. Relevant data extracted from each study (purpose, design, sample and setting, results, and indications for future research), were reviewed and grouped with other study findings that had similar outcomes and meanings. Data interpretation and synthesis of knowledge resulted from summarizing and comparing findings to identify themes that reflect insight relative to the lower prevalence of EOL ACP and AD completion rates among AAs. Eight general themes were extracted from this iterative process using the data analysis and interpretation method described by Melnyk & Fineout-Overholt (2011) which were then scored using the Sirriyeh et al. (2012) quality evaluation tool. Several similar and interrelated themes were identified in multiple studies; those identified having higher quality research scores were weighted more prominently in consolidating major themes reported here.
CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

Results

Synthesis of Findings

After enactment of the PSDA, studies were undertaken to determine if the statute was impacting ACP. Research completed after enactment, and more recent studies also, reveal the statute has made minimal if any change in the rate of AD completions, especially among minority groups (Johnson, Zhao, Newby, Granger, & Granger, 2012). Table 2 illustrates multi-factorial influences including: (1) demographic variables, (2) cultural distinctives related to patient autonomy, (3) mistrust of the US healthcare system, (4) low health literacy, (5) belief that timing of death is in God’s hands, (6) desire for aggressive interventions at EOL, (7) presence of comorbidities, and (8) family and communal decision making, as reasons negatively impacting ACP (Koss & Baker, 2017; Morhaim & Pollack, 2013; Rao et al., 2014; Waite et al., 2013). Each of these influences will be discussed in the following section.

Demographic independent variables as AD completion moderators. The low rate of AD completion among AAs related to demographics has been reported in multiple studies (Huang, Crowther, et al., 2016; Rao et al., 2014; Sanders et al., 2016). This disparity was confirmed in a large cross-sectional internet survey of 2150 adult participants by Carr (2012) who used regression analysis to identify statistically significant specific variable relationships among the demographic characteristics that moderated ACP variables. Data were collected by the Knowledge Networks internet survey among a nationwide sample and statistics gathered to assess prevalence of ACP among married or cohabitating adults aged 18-64, (n = 2111). Dependent variables included: (1) participant has had a conversation about healthcare preferences at EOL with a family member or healthcare provider, (2) participant has designated a proxy via a DPAHC, and (3) possession of a LW or AD (Carr, 2012). Bivariate analysis
indicated that WA participants were more likely to have completed all three of the dependent variable actions compared with AAs as follows: has a LW (25% vs 16%), has named a DPAHC (28% vs 21%), and had discussions about EOL treatments (60% vs 44%) (Carr, 2012).

Multivariate analyses were adjusted controlling for independent demographic variables (age, gender), family status (marital status, parental status), socioeconomic status (employment status, home ownership, educational level, income), and health status (self-assessment of physical health). Regression analysis of the data around the three outcomes (dependent variables) controlling for demographic characteristics to explain individual variance, resulted in only two relationships that were significant at the $p < .05$ level. First, disparity in AD completion rates between WAs and AAs was significant and moderated by education (higher education levels reduce difference in odds ratio [OR]); second, having had discussions about EOL with family or providers was moderated by home ownership (Carr, 2012).

Ko and Lee (2014), using regression analysis to control for independent demographic variables of gender, education, income, and spirituality among 256 low-income older adults, corroborated Carr’s (2012) findings that race/ethnicity alone is not a significant predictor of AD completion. These results are in contrast to a study by Johnson et al. (2008) that reported AAs were less likely (35.5% versus 67.4%, $p < .001$) to have an AD or DPAHC than WAs; Johnson et al. also used logistic regression analysis of demographic data, and reported race as a valid predictor of AD completion. Huang, Neuhaus, et al. (2016), in their qualitative cross-sectional study among a nationwide survey of adults 50 and older, reported comparable results to Ko and Lee, and Carr’s findings, again using regression analysis to control for demographic variables, religious characteristics, and personal health values, finding AAs were less likely to possess an AD compared to WAs OR = 0.42, 95% confidence level [CI] = 0.24-0.75.
CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

**Cultural distinctives related to patient autonomy.** Patient and family culture includes values, beliefs, and traditions shared in common among a group, family, or population that guide thinking, doing and being (Giger et al., 2006). Patient autonomy and healthcare decision making have traditionally been thought of as cornerstones of EOL care. Salient findings from the Torke et al. (2005) study revealed that the cultural values, beliefs, and lifeways of AAs often do not fit with the assumed values of patient autonomy, informed decision making, truth telling, and control over the dying process. Findings by Wicher and Meeker (2012) confirmed this cultural distinctive, stating “Not every cultural group ascribes autonomy to the individual, and for them this model [autonomy paradigm] may conflict with or neglect important values” (p. 29). This finding may explain a large part of lower rates of ACP among AAs.

Ideas of autonomy, informed decision making, truth telling, and control over the dying process as valued by the majority WA perspective have been interpreted as “justification for mandating a patient’s duty to engage in medical decision making” (Volker, 2005, p. 442). However, culturally congruent nursing care must include an opportunity for individuals not to engage in ACP, particularly if ACP is not congruent with familial values, beliefs, and traditions (Giger et al., 2006; Volker, 2005; Wicher & Meeker, 2012).

**Mistrust of the healthcare system.** Another factor that impacts formal ACP among the AA community is mistrust of the healthcare system, resulting from medical mistreatment dating back centuries, and the more recent Tuskegee Syphilis experiment (Katz et al., 2008). The Tuskegee study is the infamous clinical study conducted between 1932 and 1972 by the US Public Health Service where 399 poor AA Alabama sharecroppers were observed to assess the natural progression of untreated syphilis. The men were never told of their diagnoses, nor were they treated even after penicillin was found to be an effective cure for the disease. These historic
atrocities contribute to general mistrust of the healthcare system by AAs as they often do not believe the information provided to them is truthful or in their best interest (Giger et al., 2006; Volker, 2005). Mistrust has been reported in many studies, most in the context of decreased use of ADs. Findings revealed that AAs discuss EOL care preferences with trusted family and clergy, but often do not have written documents due to fear of receiving too little or lower quality care if preferences are written (Ko & Lee, 2014; Piamjariyakul, Myers, Werkowitch, & Smith, 2014; Rhodes et al., 2015; Robinson, 2016; Waite et al., 2013; Wicher & Meeker, 2012).

**Health literacy and lack of knowledge.** Since passage of the PSDA, interventional studies have been conducted among diverse population groups to understand factors that impact continued low AD completion rates. In their cross-sectional descriptive study, Johnson and colleagues (2012) at Duke University Medical Center, with 505 adult patients of diverse racial ethnicities receiving inpatient care (WA: n = 346, Minority: n = 159) sought to determine if health literacy impacted completion of ADs. Results indicated that 64% of the participants did not have an AD. Thirty-four percent of those without ADs did not understand what an AD was, and thus responded negatively when asked if they were interested in creating an AD document.

A study by Waite et al. (2013) conducted in Chicago among 784 adults aged 55-74 sought to examine the relationship between literacy and other individual factors of AD possession. Literacy varied significantly along racial lines; 47.4% of AAs had adequate literacy, contrasted with 88.8% of non-AAs. Using multivariate analysis, low literacy (risk ratio [RR] = 0.45, 95% CI = 0.22-0.95) and AA race (RR = 0.64, 95% CI = 0.47-0.88) were significantly associated with lower rates of AD possession. Melhado and Bushy (2011) also reported low health literacy among AA patients as a factor impacting EOL planning, finding that participants sometimes perceived ACP questions as addressing euthanasia or assisted suicide, thereby
impacting lower rates of AD completion. Many other studies have reported low health literacy as a factor contributing to low AD completions among AAs, finding participants thought having ADs might limit health care options and services (Ko & Lee, 2014; Koss & Baker, 2017; Rhodes et al., 2015; Robinson, 2016; Wicher & Meeker, 2012).

**Belief that time of death is in God’s Hands.** Study findings report a very common theme among AA participants regarding their faith in God and belief that life and death are determined by Him. Garrido et al. (2014), in a quantitative prospective study completed with 606 patients from outpatient clinics across five states from 2002-2008, reported that WA patients were significantly more likely to have a *Do Not Resuscitate* order (45%) than AA (25%) patients (p<.001). Further supporting AAs strong belief that time of death is in God’s hands, Garrido et al. (2014) reported: (a) AAs preferred more aggressive life-prolonging procedures, (b) had strong religious beliefs, (c) belief that God determines length of life, and (d) lower rates of ACP were reported among AA participants. The Torke et al. (2005) study also confirmed AA participants believe EOL is in God’s hands, and making personal EOL care plans ahead of time would be preempting God’s control over life and death. Several other studies documented similar strong spiritual beliefs about EOL and ACP among AAs with similar findings (Carr, 2012; Ko & Lee, 2014; Rhodes et al., 2015; Robinson, 2016; Wicher & Meeker, 2012).

**Desire for aggressive life-sustaining treatments.** A qualitative study by Johnson et al, (2008) reported AAs greater preference for life-sustaining treatments even with terminal diagnoses, than WAs (19.8% versus 16.1%, p < .001). Similarly, additional studies (Koss & Baker, 2016; Wicher & Meeker, 2012) reported that AAs tend to seek aggressive life-prolonging interventions (also relates to mistrust of the US healthcare system), stating that without aggressive interventions, they feel they would be left to die. This cultural distinctive is also
interrelated with the spiritual belief that God determines life and death, therefore all possible life-sustaining medical interventions should to be provided, as God ultimately controls time of death (Koss & Baker, 2017; Rhodes et al., 2015; Wicher & Meeker, 2012).

Family/communal decision making. The literature supports that WAs tend to express EOL wishes in formal AD documents yet AAs are more likely to depend on family members and trusted clergy to communicate preferences at EOL to healthcare professionals (Giger et al., 2006; Hlubocky, 2014; Piamjariyakul et al., 2014; Volker, 2005; Wicher & Meeker, 2012). The desire for EOL communal decision making with trusted family and clergy has been documented, and is likewise interrelated to mistrust of the healthcare system by AAs (Robinson, 2016; Torke et al., 2005; Wicher & Meeker, 2012). Communal decision making is also closely related to the ideas of autonomy and self-determination, yet many AAs prefer that these decisions be determined by those individuals closest and dearest to them, rather than doing so personally.

Comorbidities. Another finding from the study by Johnson et al. (2012) indicated the only significant predictor of AD completion was the number of comorbid illnesses as determined by frequency and distribution of demographic and clinical characteristics. Analysis using t-test for continuous variables and Mantel-Haenszel odds ratio for categorical variables indicated patients with zero or one comorbid illnesses were 70% less likely to have completed an AD than patients with two or three comorbidities OR = 0.3; 95% CI 0.1-1.0; p = .04 (Johnson et al., 2012). A qualitative study by Piamjariyakul et al. (2014) using open-ended questions in individual interviews among 30 ethnic minority patients with severe cardiovascular illnesses found that about 50% (more than double the commonly reported minority AD rate) had engaged in some form of ACP. These studies highlight the impact of comorbidities on the rates of ACP.
Comparable results have been reported in other studies (Campbell et al., 2007; Garrido et al., 2014; Huang, Neuhaus, et al., 2016; Ko & Lee, 2014).

**Discussion**

ADs are useful tools that aid in providing care appropriate with the wishes of patients in EOL situations. Studies conducted to assess changes in AD completion rates among the general population and ethnic population groups after enactment of the PSDA in 1991 reveal only slight changes in rates among the general population simply by healthcare facilities adhering to the requirements of the PSDA. In accordance with this finding, in a report to Congress, Assistant Secretary of DHHS stated, “In general, this Act did not reduce unwanted aggressive treatment at the EOL or its associated costs, perhaps because advance directives are underused” (U.S. Department of Health and Human Services, 2008, p. viii). Study findings confirmed that clinicians aiding and providing patients with educational materials alone, does not significantly increase the creation of ADs (Lovell & Yates, 2014; Zager & Yancy, 2011).

Rates of AD completion and ACP among the AA population are lower than among the general population. Research details the impact of multi-factorial influences why AAs are less likely to implement ACP. Findings of poor health literacy, mistrust of the healthcare system, strong faith in God coupled with the desire for aggressive life-prolonging treatments, desire to include family and clergy in EOL decision making, and the presence of comorbidities all impact attitudes about EOL ACP among AAs. Well documented among this population is the difference in cultural values regarding patient autonomy, informed decision making, truth telling, and control over the dying process. These values are more widely held among the majority WA population, and are the foundation of the PSDA. A gap in knowledge exists regarding how to provide culturally congruent nursing care at EOL for AA individuals and families. Nurses
knowledgeable in providing culturally competent care understand the PSDA mandates could be construed as cultural imposition on minority patients and families, if patients are expected or coerced to “comply” with creation of ADs.

The results of this review reinforce the disparity in ACP and AD use among AAs. This yet unsolved problem causes undue personal, spiritual, and financial stress for AA patients and family members when EOL care preferences have not been communicated or documented.

**Implications for cultural congruent nursing practice**

The PSDA mandates clinicians provide written educational materials and offer patients help completing ADs; often this responsibility is incorporated into nursing care at initial or admission patient assessment. The PSDA has had limited impact on increasing completion of ADs. Nurses need to understand that patients may not embrace EOL care planning due to their differing cultural beliefs and traditions. Nurses must be sensitive and respectful of the values and practices of patients from diverse cultures, and initiate conversations about EOL and ACP with open-ended questions that facilitate patient trust and sharing within the context of complex beliefs, traditions and lifeways. Knowledge gained from this IR has the potential to inform and improve nursing care of patients and families facing EOL situations. Future research is needed to promote equity in EOL ACP among minority population groups.

**Limitations**

Limitations of this IR include that the search strategy implemented may have failed to retrieve all applicable articles of studies that would inform understanding of EOL perspectives among AAs. Another limitation is that many of the included studies used convenience sampling which may not be representative of the population. Search limits that focused on general nursing knowledge about ADs and prevalence of ACP by ethnicity among the general population, may
have inadvertently screened out relevant research that would have added yet additional perspective to this complex issue. Further, research completed but not published, and therefore inaccessible, is also a limiting source of the findings reported.

**Conclusion**

This IR identified cultural perspectives influencing EOL beliefs, traditions and practices among AAs. Low AD completion rates reflect multi-factorial influences impacting personal decisions about EOL planning. While no one identified factor explains all the deference to ACP by AAs, all factors influence EOL care planning both individually and collectively.
Figure 1. PRISMA 2009 Flow Diagram
# CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

## Table 1.

### Summary of Findings Related to ADs and ACP among African Americans

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<th>Author/Year</th>
<th>Purpose</th>
<th>Sample/design</th>
<th>Results</th>
<th>Critique/Future Direction</th>
<th>Quality</th>
</tr>
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<tbody>
<tr>
<td>Campbell et al., 2006</td>
<td>To develop a model to assist nurses in promoting self-determination for ADs</td>
<td>Descriptive study using multinominal logistic regression to assess 15 factors and covariates on completion of AD among deceased nursing home residents</td>
<td>Of the 15 factors that could impact completion of an AD, only receiving AD information, attitude index, and health literacy score were significant</td>
<td>Study using Bandura’s Social Cognitive Theory to explain the relationship of possible triadic determinants of EOL decisions</td>
<td>90.5%</td>
</tr>
<tr>
<td>Carr, 2012</td>
<td>To determine if Whites, Blacks, Latinos, and Asians in the US differ in their rates of ACP within racial group heterogeneity, and explanations for not completing ACP?</td>
<td>Secondary analysis of cross sectional internet survey of 2150 participants age 18 - 64 yrs. using the Knowledge Networks survey, in conjunction with the National Center for Family and Marriage Research at Bowling Green St University</td>
<td>Descriptive statistics for race and ethnicity calculated; logistic regression models constructed to determine impacts of multivariate analysis; AAs 66% more likely to have discussions than LW or DPAHC</td>
<td>Study completed with individuals in couple relationships, among younger adults, thus possibly resulting in less generalizable findings. Study limited to English speakers—may negatively impact the results for Latinos &amp; Asians.</td>
<td>88.1%</td>
</tr>
<tr>
<td>Frahm et al., 2015</td>
<td>To examine relationship between race (White, Black, Hispanic, and Asian) and AD, hospice, and hospitalization at EOL among deceased nursing home residents</td>
<td>Secondary data analysis using 2007 Minimum Data Set for 183,841 nursing home residents who had a full assessment completed &amp; who died during 2007</td>
<td>Descriptive statistics were explored and linear regression fitted to each dependent variable, AD measures, hospice use, &amp; hospitalizations with “race” as the main predictor. AAs elders were significantly less likely to have a DPAHC, LW, and DNR orders, than WAs.</td>
<td>Secondary data may not capture the influence of ACP, hospice use, or hospitalizations, or allow for a comprehensive relationship between variables. Future studies should include primary study data, including qualitative data also.</td>
<td>78.6%</td>
</tr>
<tr>
<td>Garrido et al., 2014</td>
<td>To evaluate extent EOL values associated with DNR rates within racial/ethnic groups among pts w/ advanced CA</td>
<td>Convenience sample cross sectional prospective study using the Coping with CA study data to track incidence of DNR orders w/606 pts, 437 non-Latino White, 93 Black, 76 Latino. Pts from 5 states in outpatient clinics followed them median 4 months until death</td>
<td>Rates of DNR orders differ along racial-ethnic lines (25%-AAs, &amp; 45%-WAs), as do LSTs. Illness acceptance &amp; spiritual beliefs not assoc. w/AA DNR status</td>
<td>Results limited by small N among Black and Latino participants. Need future empirical study of social influences that change EOL preferences among pts w/ CA</td>
<td>76.2%</td>
</tr>
<tr>
<td>Hendricks-Sloan et al. 2016</td>
<td>To ID parishioner experiences and beliefs about EOL care/desire for church based programs addressing ACP and EOL</td>
<td>Cross-sectional survey conducted using a 5 question, Likert-scale response of survey cards distributed to parishioners of 2 large AA Baptist churches across 4 weekends; 930 responses were collected</td>
<td>Researcher developed 5-question survey: 70% cared for someone at EOL, 97% believe that good EOL care is important, 60% have spoken with a decision maker if they cannot make decisions, &amp; 91% would welcome church provided information re: EOL care</td>
<td>Determination of culturally appropriate content and delivery of the ACP faith based intervention, that embraces religion and spirituality</td>
<td>71.4%</td>
</tr>
<tr>
<td>Huang, C. S. et al., 2016</td>
<td>To investigate the feasibility of an intervention, the Thinking Ahead</td>
<td>Mixed method RCT convenience and snowballing sample, N=30, of AAs living in Southern</td>
<td>Perceived barriers to ACP: lack of education about ACP, lack of family/social support, Similar study with larger sample and not limited to a specific geographic area. Also, using a longitudinal</td>
<td>76.1%</td>
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<tr>
<td>Study Details</td>
<td>Research Design</td>
<td>Methodology</td>
<td>Findings</td>
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<td><strong>Project, to increase ACP among AAs in the southern US.</strong></td>
<td>Prospective, intervention-control group design, a 3-part intervention: motivational interviewing, an evidence-based ACP facilitation program, and a health literacy AD explanation written at grade 5 reading level</td>
<td>states in the US.</td>
<td>sense of hopelessness, mistrust of doctors, busyness-no need to discuss future plans, and reticence to talk about death and future care</td>
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<tr>
<td><strong>Huang, I. A., Neuhaus &amp; Chiong, 2016</strong></td>
<td>Cross-sectional panel design online survey study of medical treatments preferences, &amp; to assess AD possession 3418 online questionnaires from US adult respondents aged 50+</td>
<td>AAs were significantly less likely to have ADs, 44.0% of WA, 24.0% of AAs, at (p&lt;0.001) even adjusting for demographics, spirituality, &amp; cultural values.</td>
<td>Study re: employment transitions and access to information may be useful in promoting ACP among minorities</td>
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<tr>
<td><strong>Johnson, Kuchibhatla, Tulsky, 2008</strong></td>
<td>Cross-sectional qualitative single point in time survey of 205 community dwelling adults aged 65+ receiving primary care at Duke University Health System</td>
<td>AAs: greater preference for LST, distrust of HC system, spiritual beliefs, discomfort discussing death, impacting AD completions. In unadjusted analysis, WAs had 4.5 times greater odds of AD (p&lt;0.001). Multi-variate analysis reduced relationship between race and having an AD</td>
<td>HC providers, researchers, and policy makers need to design, test, and implement EOL ACP programs that accommodate a range of individual and cultural beliefs, values and preferences</td>
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<td><strong>Johnson, Zhao, Newby, Granger, Granger, 2012</strong></td>
<td>Cross-sectional, descriptive, exploratory study of 505 adult patients pts. admitted to major university MC, 03/08 – 06/09, asking if they had AD, or interested in creating one, and 3 open ended questions to ID qualitative themes about EOL and AD</td>
<td>Mean age of 61.9 years, (68.5% white), 64% did not have AD. Of the 64% without AD, 34% indicated they did not understand what AD was when asked if they had one, therefore they declined not knowing what was being asked</td>
<td>Simple asking pts if they have an AD is not sufficient; providing meaningful discussions with pts and families will allow them to make an educated decision regarding ACP and ADs</td>
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<tr>
<td><strong>Ko &amp; Lee, 2014</strong></td>
<td>Cross sectional design to assess completion of ADs and ethnic racial influencers. 256 participants from 2 low income housing facilities &amp; a senior center in urban California. Inclusion aged 60+ &amp; cognitively competent as measured by Short Portable Mental Status Questionnaire.</td>
<td>Both AAs and WAs had poor knowledge (35%) and possession (20%) of ADs; Logistic regression for race/ethnicity on AD completion did not sig. explain AD completion when controlling for other factors.</td>
<td>Replicate study with participants outside of strictly a metropolitan area, and with more than just low income individuals.</td>
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<tr>
<td><strong>Koss &amp; Baker, 2016</strong></td>
<td>Prospective longitudinal survey data: Health and Retirement Study, by proxy for 5832 deceased 2001-2012, aged 51+ at time of enrollment</td>
<td>Using logistic regression models, the odds of having an AD for AAs were 16% of the odds for WAs at (p&lt;.001), but rates among AAs are increasing.</td>
<td>Identify factors impacting older AAs preventing discussions about EOL preferences</td>
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## CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Objective of Study</th>
<th>Methodology</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Lovell et al., 2014</td>
<td>To assess uptake of ACP in palliative care; a systematic review from Jan 2008 through Dec 2012</td>
<td>Systematic ROL using Medline, CINAHL, and Embase from Jan 2008 through Dec 2012. Primary research reporting on ACP in a palliative care setting</td>
<td>Positive assoc with ACP are age, advanced education, and white race. Negative assoc with ACP are AA race, poor EOL health literacy, and HC professionals’ lack of understanding to discuss ACP with pts.</td>
</tr>
<tr>
<td>Melhado &amp; Bushy, 2011</td>
<td>To ID cultural preferences and factors contributing to reduced EOL ACP among AAs, also assess how health literacy impacts ACP EOL care disparities</td>
<td>ROL, but sample/search parameters not disclosed in the article</td>
<td>ROL identified items to include in 10-item Health Literacy Skills Instrument, assesses ability to use &amp; understand health related information, used with the Mishel Uncertainty in Illness Scale to assess health literacy and mistrust of the HC system.</td>
</tr>
<tr>
<td>Morhaim &amp; Pollack, 2013</td>
<td>To assess prevalence of AD use, demographic indicators, attitudes towards ADs in MD</td>
<td>Cross sectional survey of adults &gt; 18 years old in Maryland (MD)</td>
<td>Approximately 1/3 of adults in Maryland have completed an AD, with twice as many WAs having ADs as AAs</td>
</tr>
<tr>
<td>Piamjariyakul et al., 2014</td>
<td>To explore EOL preferences and assess prevalence of signed ADs or if pt has discussed w/anyone EOL care they desire</td>
<td>Cross sectional survey w/open ended questions, interviews w/volunteer convenience sample of 30 ethnic minority pts with chronic CVD illnesses receiving nursing care in Kansas</td>
<td>5 themes for EOL decisions; comfortable environment, family involvement, no life-prolonging procedures, pain free, good relationship with HC professional. 50% had AD</td>
</tr>
<tr>
<td>Rao et al., 2014</td>
<td>To ID characteristics of US adults about having an AD, and factors associated with completion, i.e. chronic condition, pain, etc.</td>
<td>Cross sectional panel survey conducted via postal mail w/7946 adult (18+ yrs) respondents to the Health Styles Survey; data post-stratified to reflect the current US population</td>
<td>Overall 26.3% of respondents had completed and AD, and completions were associated with older age, higher education, higher income. Also, less frequent among non-white respondents</td>
</tr>
<tr>
<td>Rhodes, Batchelor, Lee &amp; Halm, 2015</td>
<td>To ID barriers to use of EOL care options i.e. ADs, palliative care, and hospice among AAs</td>
<td>Cross section w/semi-structured interview of a purposive sample of 12 hospice/palliative care providers and reps of nat’l HC organizations</td>
<td>Barriers identified were: lack of knowledge, desire for aggressive treatments, family resistance to hospice, and lack of insurance</td>
</tr>
<tr>
<td>Sanders, Robinson &amp; Block, 2016</td>
<td>To understand factors impacting ACP among AAs, to guide future research.</td>
<td>Systematic IR of literature. Searched Medline, Embase, and World of Science databases for ACP literature with AAs involved.</td>
<td>Factors that impact ACP for AAs are inter-related and may be the result of historical realities that have shaped values and beliefs.</td>
</tr>
<tr>
<td>Shapiro, 2015</td>
<td>To determine if ADs direct the care received by patients</td>
<td>3 yr prospective observational study of 2216 pts admitted to neurological or medical</td>
<td>Findings are that ADs or other ACP documents have little impact on alleviating the stress of compared with pts w/no ADs, families and pts w/ADs are more likely to talk about pt preferences re:</td>
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<tr>
<td>Study</td>
<td>Objective</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Torke et al. 2005</td>
<td>To characterize views of seriously ill AA pts at EOL.</td>
<td>Cross sectional qualitative descriptive study using a semi-structured in-depth interview with open ended questions w/23 AA pts. facing serious illness in a large urban public hospital</td>
<td>Themes identified: Desire to die, Hope for a cure, Comfort care, In God’s hands, Limited role of doctor.</td>
</tr>
<tr>
<td>Volker 2005</td>
<td>To present results of ROL re: autonomy-control and ethnicity relative to EOL.</td>
<td>ROL, but sample/search parameters not disclosed in the article</td>
<td>Control over EOL preferences &amp; ethnicity is complex, &amp; some cultures do not engage in ACP.</td>
</tr>
<tr>
<td>Waite et al., 2013</td>
<td>To examine effect of literacy &amp; individual factors on prevalence of AD among ethnicities.</td>
<td>Cross sectional survey using F2F structured interview w/784 adults aged 55-74 from 5 clinics in Chicago.</td>
<td>AAs had lower literacy (&lt;50% vs 89%-non-AA); literacy &amp; race strongly associated w/AD completion, as were older age, higher education &amp; income, employment, &amp; fewer chronic conditions.</td>
</tr>
<tr>
<td>Wicher &amp; Meeker, 2012</td>
<td>To ID AAs preferences re: EOL care &amp; decision making.</td>
<td>Systematic ROL: 46 studies, 1990-2010 using CINAHL, Psych Info, Cochrane Library, Medline, &amp; PubMed, for AAs EOL preferences.</td>
<td>Prevalence of ADs among AAs less than WAs, re: lack of knowledge, mistrust of HC system, communal decisions, spirituality, desire LSTs.</td>
</tr>
<tr>
<td>Zager 2011</td>
<td>To assess cultural norms and practices about ADs, &amp; to seek an AD method that addresses varying cultural values and beliefs.</td>
<td>ROL including both quantitative and qualitative studies: PubMed, Cochrane, and Google Scholar searched &amp; yielded &gt; 86,000 articles. Ten articles met inclusion criteria &amp; included in the synthesis.</td>
<td>Cultures, values, &amp; beliefs drive attitudes about ADs; From RCTs, systematic review of qualitative studies, 3 themes emerged: 1-ADs should be culturally sensitive, 2-HCPs need to understand cultural differences to support a range of values, beliefs, and preferences, 3-Importance of educ. pts and HCPs re. ADs and how used.</td>
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Table 2.
Factors Influencing Lower AD Rates among African Americans

<table>
<thead>
<tr>
<th>Factor</th>
<th>Authors Citing This Phenomena</th>
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<tbody>
<tr>
<td>Demographic moderators</td>
<td>Carr, 2012</td>
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<td></td>
<td>Huang, Neuhaus &amp; Chiong, 2016</td>
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<td></td>
<td>Ko &amp; Lee, 2014</td>
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<tr>
<td></td>
<td>Rao, Anderson, Lin &amp; Laux, 2014</td>
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<tr>
<td>Cultural distinctives related to patient autonomy</td>
<td>Giger, Davidhizar &amp; Fordham, 2006</td>
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<td>Huang, Neuhaus &amp; Chiong, 2016</td>
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<tr>
<td></td>
<td>Ko &amp; Lee, 2014</td>
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<tr>
<td></td>
<td>Piamjariyakul, Myers, Werkowitch &amp; Smith, 2014</td>
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<td></td>
<td>Robinson, 2016</td>
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<td></td>
<td>Torke, Garas, Sexson &amp; Branch, 2005</td>
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<td></td>
<td>Volker, 2005</td>
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<td>Wicher &amp; Meeker, 2012</td>
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<tr>
<td>Mistrust of the healthcare system</td>
<td>Giger, Davidhizar &amp; Fordham, 2006</td>
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<td></td>
<td>Huang et al., 2016</td>
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<td>Ko &amp; Lee, 2014</td>
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<td>Koss &amp; Baker, 2016</td>
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<td>Piamjariyakul, Myers, Werkowitch &amp; Smith, 2014</td>
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<td>Waite et al., 2013</td>
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<td>Wicher &amp; Meeker, 2012</td>
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<td>Health literacy</td>
<td>Campbell, Edwards, Ward &amp; Weatherby, 2007</td>
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<td></td>
<td>Huang et al., 2016</td>
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<td>Johnson et al., 2012</td>
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<td>Ko &amp; Lee, 2014</td>
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<td>Lovell &amp; Yates, 2014</td>
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<td>Wicher &amp; Meeker, 2012</td>
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<tr>
<td>Importance of religion and belief that death is</td>
<td>Garrido, Harrington &amp; Prigerson, 2014</td>
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<td>in God’s hands</td>
<td>Giger, Davidhizar &amp; Fordham, 2006</td>
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<td></td>
<td>Wicher &amp; Meeker, 2012</td>
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<tr>
<td>Aggressive life-sustaining treatments</td>
<td>Garrido, Harrington &amp; Prigerson, 2014</td>
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<td>Giger, Davidhizar &amp; Fordham, 2006</td>
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<td>Wicher &amp; Meeker, 2012</td>
</tr>
<tr>
<td>Presence of comorbidities</td>
<td>Johnson, Zhao, Newby, Granger &amp; Granger, 2012</td>
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<tr>
<td>Family structure and communal support in decision making</td>
<td>Rhodes, Batchelor, Lee &amp; Halm, 2015</td>
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<td>Robinson, 2016</td>
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<td>Wicher &amp; Meeker, 2012</td>
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CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

References


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Advance directive completion rates among the general population are low, even among adults age 50 and older. Studies report even lower completion rates among African Americans (AA) due to demographic variables, cultural distinctives related to patient autonomy, mistrust of the healthcare system, low health literacy, strong spiritual beliefs, desire for aggressive interventions, importance of family-communal decision making, and presence of comorbidities (Koss & Baker, 2017; Morhaim & Pollack, 2013; Rao et al., 2014; Waite et al., 2013). The largest disparity in AD rates is between AAs at 17-24%, and White Americans (WAs) at 30-45% (Garrido et al., 2014; Huang, Neuhaus, et al., 2016; Rao et al., 2014). Implementation of ADs promote patient and family centered care, and should be encouraged. Similarly, hospice and palliative care as ACP options are utilized less among AAs than WAs (Frahm et al., 2015; Lovell & Yates, 2014).

Aims

Problem of Interest. This study sought to identify culturally based meanings, expressions, and practices related to ADs among AAs in the US. The low rate of EOL ACP among AAs has potentially negative personal, social, and financial implications for AA individuals and families.

Nurses educate patients and families about EOL ACP as mandated by the PSDA of 1991, yet often are unfamiliar with potential barriers to AD completion. Implementation of ADs promote patient and family centered care, and are encouraged by many in the healthcare community. A comprehensive Integrative Review of Literature (IR) was completed for this study confirming the disparity in ACP and use of ADs among AAs in the US (Huang, Crowther, et al., 2016; Rao et al., 2014; Sanders et al., 2016). Additionally, the IR identified multi factorial
CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

cultural distinctives of AAs that negatively impact ACP. Five themes were discovered impacting use of ADs among the AA population: 1) moderators to personal patient autonomy that include familial and communal decision making, 2) mistrust of the healthcare system, 3) low health literacy and level of education, 4) importance of religion and belief that life and death are in God’s hands, and 5) desire for aggressive life sustaining treatments at EOL (Carr, 2012; Garrido et al., 2014; Giger et al., 2006; Hlubocky, 2014; Ko & Lee, 2014; Koss & Baker, 2017; Melhado & Bushy, 2011; Piamjariyakul et al., 2014; Torke et al., 2005; Volker, 2005; Waite et al., 2013; Wicher & Meeker, 2012). Unfortunately, understanding of interventions to help AAs embrace ACP that do not conflict with this population’s cultural beliefs and traditions, still eludes the healthcare community, causing undue personal, spiritual, and financial stress for AA patients and families (Rhodes et al., 2015). This study seeks to understand underlying beliefs, traditions, and cultural influences impacting EOL care planning among AAs.

Long term objectives of the student’s program of research. Consistent with the 2013 National Institute of Nursing Research report, Building Momentum: The Science of End-of-Life and Palliative Care, and the Institute of Medicine Report Dying in America, the proposed research sought new understanding in the areas of EOL and ACP (Institute of Medicine of the National Academies, 2015; National Institutes of Health, 2013), appropriate to the following specific goals in the National Institute of Nursing Research document:

- Improve understanding of the complex issues and choices underlying EOL care planning
- Create new communication strategies among clinicians, patients, families, and communities to promote decision making regarding complex treatment and care options in the face of life threatening illness and/or natural EOL.
CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

The long-term trajectory of the study topic by this researcher is to continue exploring disparities in EOL ACP among the AA population living in the US. Additionally, research among other populations including Hispanics, American Indian/Alaska Natives, and Asian Americans will also be conducted, seeking to elucidate the generational values, beliefs, and traditions that may be impacting EOL culture care expressions, meanings, patterns and practices among each of these population groups.

**Specific Aims.**

1. To identify and describe EOL and ACP cultural perspectives, beliefs, and practices among AAs living in the U.S.

2. To identify and describe the culturally based meanings, expressions, and traditions related to ADs among AAs living in the U.S.

3. To identify and describe nursing care practices that facilitate culturally congruent EOL ACP among AAs living in the U.S.

**Research Questions.**

1. What are the EOL and ACP cultural perspectives, beliefs, and practices among AAs living in the U.S.?

2. What are the culturally based meanings, expressions, and traditions related to ADs among AAs living in the U.S.?

3. What are nursing care practices that facilitate culturally congruent EOL ACP among AAs living in the U.S.?

**Study Significance and Background**

End of life care that honors the wishes of individuals and families is a complex issue with few easy answers. According to Koss and Baker, “advance care planning is a process through
which competent adults can discuss their healthcare goals and communicate their preferences about life-sustaining treatment in the event they are ever unable to make medical decisions for themselves” (2017, p. 2). When ACP is not completed, healthcare decision making for incapacitated loved ones can be stressful and difficult, resulting in family members often choosing life-prolonging interventions including extensive and invasive medical procedures (Hendricks Sloan et al., 2016; Sanders et al., 2016).

This dilemma has long been a topic of conversation by ethicists, politicians, healthcare professionals, and individual families. High profile bioethics cases like Karen Ann Quinlan in 1976, Nancy Cruzan in 1990, and more recently Terri Schiavo in 2005 have prompted public discourse about medical intervention to maintain artificial respiration and circulation, or to allow natural death to occur (Annas, 2005). While public conversation waxes and wanes relative to national and global awareness of EOL care issues, healthcare decision making by a surrogate (proxy or family member) is difficult without prior ACP as a guide for EOL care. The above-mentioned cases are more complex than the singular issue of EOL ACP, however the Quinlan and Cruzan cases and the public discourse they prompted were the impetus of the Patient Self Determination Act (PSDA) of 1991 (Congress, 1990).

Passage of the PSDA was intended to encourage creation of ADs to bring EOL legislative uniformity across the nation, and when in place, require the adherence to ADs by healthcare providers (Breu, 2012). To facilitate AD creation, the PSDA requires health care facilities receiving Medicare and Medicaid funding to educate and offer patients the option of creating AD documents with assistance from facility staff. Specifically, PSDA requirements include: (a) clinical facilities maintain written institutional policies requiring clients be asked about ADs, (b) facilities educate clinical staff about the value of AD completion, (c) require clinical staff to ask
and document if clients have an AD, (d) provide clients with written educational information about ADs, and (e) notify clients in writing that provision of healthcare is not contingent upon completion of an AD (Institute of Medicine of the National Academies, 2015).

ADs, also referred to as Living Wills (LW) or Durable Attorney for Healthcare (DPAHC), are documents describing individuals’ EOL care preferences (Institute of Medicine of the National Academies, 2015). ADs provide family members and medical professionals with information needed to honor healthcare treatment choices in case of future incapacity, and may include designation of a surrogate(s) to make healthcare decisions on behalf of the patient. Surrogate decision makers are typically named in a DPAHC document (Ko & Lee, 2014; Shapiro, 2015; United States Government Accountability Office, 2015).

**Synthesis of literature.** Not long after enactment of the PSDA, studies were undertaken attempting to understand why enactment of the statute with its mandated requirement to assist patients in completing ADs was making only minimal changes in the rate of AD completions, especially among minority populations (Johnson et al., 2012). Study findings identified beliefs and cultural values among the AA population that negatively impact AD creations, but findings have been multi-facetted. Also, there have been many interventional studies conducted attempting to increase ACP among this population, yet no methodologies identified in the IR have had wide acceptance or have significantly increased EOL ACP among this population (Johnson et al., 2012; Sanders et al., 2016).

A premise of the PSDA legislation is that patients strongly value personal autonomy and the right to decide the extent and types of interventional care received at EOL. One of the themes identified in the IR as factors in low rates of ACP and AD prevalence among AAs, is this very issue of personal control over the dying process. While patient control and autonomy are at
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the foundation of bioethics in US healthcare, study findings reveal that the assumption that all cultural groups value patient autonomy, informed decision making, truth telling, and control over the dying process, are not values universally held among the AA population regarding EOL care (Torke et al., 2005; Volker, 2005; Wicher & Meeker, 2012). Further, multiple studies documented that ACP for EOL may not be congruent with the remaining multi factorial themes identified in the IR. Therefore, the mandated requirements of the PSDA for healthcare institutions to encourage and promote use of ACP, are quite likely culturally insensitive and incongruent to those in the AA community (Giger et al., 2006; Huang, Neuhaus, et al., 2016; Volker, 2005; Wicher & Meeker, 2012). Understanding this concept was foundational to the study conducted and detailed here.

The domain of inquiry (DOI) of this study was the provision of culturally congruent care at EOL for AAs living in the US. The researcher sought greater comprehension of beliefs and cultural values impacting AD completion and ACP, and to understand culturally based expressions, patterns, and practices regarding EOL among this population. Identification and understanding of cultural distinctives among the population being served are integral for providing culturally congruent nursing care (McFarland & Wehbe-Alamah, 2015). The goal of exploring culturally congruent care was toward better understanding of generic care and caring influences that may lead to improvement in the quality of life and well-being of AA individuals and families at EOL.

Gaps in nursing knowledge. ADs are useful tools to aid in providing care appropriate with the wishes of patients in EOL situations. Study findings have reported little change in the AD completion rate for the general population or among minority groups after enactment of the PSDA in 1991, simply by healthcare facilities adhering to the requirements of the PSDA that
Clinicians aid and provide patients with educational materials. Reporting to Congress, the Assistant Secretary of DHHS stated “In general, this Act did not reduce unwanted aggressive treatment at the EOL or its associated costs, perhaps because ADs are underused” (U.S. Department of Health and Human Services, 2008, p. viii). This gap in knowledge about how to educate and encourage AA minority individuals and families about ACP and the use of ADs is the overarching gap this study sought to address.

A salient gap in the literature (within the greater gap in knowledge about educating and encouraging ACP and use of ADs) exists regarding cultural values related to patient autonomy, informed decision making, truth telling, and control over the dying process. These values are more widely held among the majority white population, and are foundational to the PSDA. While this difference in values has been well documented, a gap exists about how to provide culturally congruent nursing care at EOL for AA individuals and families. Nurses knowledgeable in providing culturally congruent care will understand the PSDA mandates could be construed as cultural imposition on minority patients and families, if patients are expected to “comply” with creation of an AD. Many studies, assuming these values are universally held across cultures, have attempted to explain, educate, or intervene to correct the disparity in AD completion among AA population samples, usually with limited success. This study sought to gain knowledge about how the PSDA might be implemented in such a way that it respects the values and cultural beliefs of AAs.

The IR also identified additional themes related to cultural values and beliefs influencing EOL traditions and practices (Campbell, 2013; Garrido et al., 2014; Giger et al., 2006; Huang, Neuhaus, et al., 2016; Koss & Baker, 2017; Torke et al., 2005; Wicher & Meeker, 2012). Lower than average AD completion rates among AAs are also impacted by mistrust of the healthcare
system, low health literacy and lack of knowledge, belief that life and death are in God’s hands, and desire for aggressive life prolonging procedures at EOL. Gaps in knowledge also exist regarding how to better understand these factors impacting AAs at EOL. This study also sought to gain information for clinicians that will help them understand EOL practices and beliefs among this population.

**Significance of the study to health and nursing practice.** The PSDA mandates that clinicians provide written educational materials and offer patients help in completing ADs; often this responsibility is incorporated into nursing care at the initial patient admission assessment. This intervention has had limited impact on increasing completion of ADs, much less than might have been expected by the framers of the enactment. Nurses providing culturally congruent care must understand that patients may not embrace EOL care planning because of differing cultural values and beliefs. Knowledge gained from this study has the potential to inform and improve nursing care of patients and families faced with EOL situations. The conducted research is needed to provide equity and informed decision making for EOL ACP among AA individuals and families.

**Guiding framework.** The framework guiding the study is Leininger’s Culture Care Diversity and Universality Theory, often referred to as the Culture Care Theory (CCT) (Leininger, 2006a). Leininger held that, “care [is] the essence of nursing” and that culture and care are interdependent and intertwined such that care that is “culturally meaningful, therapeutic, congruent, and safe for people of diverse and similar cultures” is essential to human health, wellness, and survival (Leininger, 2006a, p. 4). Leininger also postulated that human care is what distinguishes nursing’s role in helping people heal, deal with disabilities and/or impending death (McFarland & Wehbe-Alamah, 2015, p. 4).
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A qualitative design was employed, using Leininger’s Ethnonursing Method (EM) to guide the data collection, analysis, and results of the study. The EM was designed by Leininger (Leininger, 2006b) to fit with the tenets of the CCT, and the principles and rationales of qualitative research methodology. It is the researcher’s desire that using the EM would facilitate illuminating cultural distinctives and commonalities related to EOL care for AAs in the U.S. Discovery of new knowledge about the beliefs and cultural values of this population regarding EOL was sought.

Preliminary Studies

Pretesting and recruitment. A preliminary study or mini-study was designed to gain insight into design of the full study and to pre-test the semi structured interview guide. The preliminary study was advertised by way of posters in two local “Free Medical Clinics” where many AA residents seek medical care. The posters asked for volunteers to assist in completing a qualitative study titled: Exploring End of Life Planning Beliefs and Values of African Americans. The poster stated the purpose of the qualitative ethnographic research study was to explore and understand EOL planning among AA Midwestern urban residents. The methodology of the preliminary study was to collect data from a convenience sample of two - three adult AA informants, age 21 and older from a pool of patients being seen at Free Medical Clinics in Midwestern cities. A semi-structured interview guide was designed to guide the interview regarding EOL planning and spark conversation about beliefs, values, and life experiences influencing decisions about personal care options at EOL.

Conclusions and implications. The preliminary study yielded no participants, thus prompting that recruitment required a different focus for this type of study, causing the researcher concern and re-thinking access to this population. Conversation with University
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faculty and other seasoned researchers indicated that seeking volunteer participants from healthcare clinics seldom results in willing informants in research. This preliminary study informed the researcher that seeking study participants may require the influence of a “gatekeeper” as someone within the population being sought, to introduce and validate the researcher, the study, and the institution to secure informants (Horton, 2014). Willing informants were sought via other organizations and institutions including churches, social groups and gatherings, and community events, utilizing community gatekeepers within these organizations.

**Research Design and Methods**

**Research Design.** The guiding framework for the proposed research was Leininger’s CCT, and the study was conducted using the EM. The EM is a research method that assists the researcher to understand the contextual cultural meaning and experiences of informants regarding the phenomena of interest (Leininger, 2006b). EM has its roots in anthropology and ethnography, but “was developed as an important means to tap vague, largely complex, covert, and unknown care and cultural phenomena in order to generate fresh data as a basis for culturally congruent care” (Leininger, 2006a, p. 20). The EM was utilized to gain understanding of this population’s attitudes regarding EOL planning and ACP choices. Leininger’s EM is a “rigorous, systematic, and in-depth method for studying multiple cultures and care factors within familiar environments of people and to focus on the interrelationships of care and culture to arrive at the goal of culturally congruent care services” (Leininger, 2006a, p. 20). The EM was developed to assess previously unknown cultural phenomena that are often intertwined with values, beliefs, and lifeways, that are sometimes elusive and concealed but are essential in order to create new
nursing knowledge regarding the DOI, and to provide culturally congruent care (Leininger, 2006a).

Foundational to the CCT is the idea that care is the essence of nursing, and that culture and care are inextricably intertwined, such that knowledge and understanding of the patient’s culture by the nurse, and how care is delivered are major influences on how nursing approaches provision of care for individuals (McFarland & Wehbe-Alamah, 2015). Central constructs of the CCT are care, culture, and the related concepts of emic and etic care practices. Leininger described care as “those assistive, supportive, and enabling experiences or ideas toward others…to improve a human condition or lifeway,” and that “caring refers to actions, attitudes, and practices to assist or help others toward healing and wellbeing” (Leininger, 2006a, p. 12). Leininger defined culture as “the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular culture that guides thinking, decisions, and actions in patterned ways and often inter-generationally” (Leininger, 2006a, p. 13). The emic or insider perspective of care includes the generic indigenous, folk, and naturalistic care modalities of human caring and includes care practices that are passed from generation to generation within families and cultures. Etic perspectives are the outsider or professional care perspectives that consist of “formal and explicit cognitively learned professional care knowledge and practices” learned primarily thorough formal nursing school, and via evidence based healthcare practices (Leininger, 2006b, p. 14). The CCT framework asserts that culturally competent care consists of both emic and etic care perspectives.

The CCT theory posits that “care that is culturally meaningful, therapeutic, congruent, and safe for people of diverse cultures” must be weighed in the balance of the values, beliefs, and lifeways of the patient, not dictated by the nurse or healthcare community (Leininger, 2006b,
p. 4). The goal of using the CCT and the EM is that nursing care is provided that individuals desire, and is culturally meaningful to them (McFarland & Wehbe-Alamah, 2015).

The Ethnonursing Method requires extended researcher interaction with informants (see Appendix B, Stranger to Trusted Friend Enabler), comprehensive and copious field notes, documentation of settings and surroundings, personal informant interviews, and use of *Leininger’s Sunrise Enabler* (see Appendix A) as a cognitive map of the CCT to “discover embedded and multiple factors related to the theory, tenets, and assumptions” of the DOI being studied (McFarland & Wehbe-Alamah, 2015, p. 24). The *Sunrise Enabler* is a graphic depiction of the many influencers of an individual’s worldview resultant of their cultural and social structure dimensions, including technological, religious and theosophical, kinship and social, cultural values-beliefs-lifeways, political and legal, economic, and education factors that all play a part in shaping culture care expressions, patterns, and practices of patients and families. Using the *Sunrise Enabler*, the EM facilitates the researcher to tease out embedded and multiple factors related to the DOI, which otherwise are so intertwined and interdependent that the researcher might miss the distinctiveness of individual cultural factors. The EM and the *Sunrise Enabler* guide the research to investigate transcultural human care phenomena, systematically uncover culture care meanings, and to discover new meanings-in-context and recurrent patterning criteria (McFarland & Wehbe-Alamah, 2015).

The goal of the CCT is to help nurses provide “culturally meaningful, therapeutic, congruent, and safe [care] for people of diverse and similar cultures” (Leininger, 2006a, p. 4). The CCT and the EM were chosen for this study to access data about peoples’ viewpoints, and culturally defined beliefs and practices related to EOL ACP, such that culturally congruent care can be identified and provided.
Setting, Sample and Sampling Procedures. Participants were sought from the AA community, from urban areas in the Midwestern US. A purposive sample with snowballing was utilized to assess the population. Inclusion criteria was English speaking, self-identified AA adult residents 1) 21 years of age and older 2) male or female residents of the US, 3) who self-report having not been diagnosed with a life-threatening illness or disease, who 4) agreed to complete the qualitative semi structured interview with the researcher, and 5) complete the personal demographics survey. Data collection was facilitated utilizing a semi-structured interview guide to ascertain the cultural beliefs, values, and traditions of the study participants as they relate to creation of EOL and ACP documents. Demographics of the study participants were also collected at the time of completion of the semi-structured interview, and included participant age, gender, race, ethnicity, income, and marital status. Interviews with the semi structured interview guide were conducted until data saturation was determined by way of identifying no new themes (Wehbe-Alamah & McFarland, 2015).

Recruitment of Informants and Interview Logistics. Achievement of the goals of the research included identification and recruitment of informants who agreed to take part in the interview/survey from among the population group meeting the inclusion criteria. Participants were sought from volunteer respondents identified from the community with the assistance of “gatekeepers” known or introduced to the researcher. Gatekeepers are individuals who are recognized in their communities as people who can be trusted and whose advice is reliable. The researcher developed relationships with several gatekeeper individuals and asked them to assist in identifying informants and providing introductions to the researcher.

The EM describes informants on two separate levels, key informants and general informants. Leininger describes key informants as those people who have the most knowledge
about the DOI (2006b). Per directives within the EM, ten to twelve key informants (or until data saturation occurs) (Leininger, 2006b; Wehbe-Alamah & McFarland, 2015) were sought to share insights about values, beliefs, and traditions of EOL ACP among the AA population. Additionally, 20-24 general informants were also sought, however general informants are not as knowledgeable as key informants although they do have knowledge about the DOI, and serve to inform the researcher for comparison of ideas and beliefs shared by key informants. Further, general informants gave the researcher additional perspective to reflect on the diversity and universality within the culture (Leininger, 2006b; McFarland & Wehbe-Alamah, 2015).

The researcher contacted gatekeepers (trusted community leaders, pastors, etc.), and explained the proposed research, asked for their assistance with identifying informants and asking them to consider participating in the study. Contact information of the researcher was distributed by gatekeepers to potential informants asking them to contact the researcher.

As willing participants who meet inclusion criteria were identified, informed consent was explained regarding the research, including agreement to be interviewed using a semi-structured interview guide. Further, all facets of the Protection of Human Subjects (described below) were be explained to the participants if they choose to participate. After consent, demographic information was obtained and the interview will began using the semi-structured interview guide to assess the participants’ understanding, values, beliefs, and traditions related to EOL and ACP. Individual interviews were conducted at that initial meeting, with follow-up phone calls from the researcher as needed when clarification was needed. Interviews were conducted in private offices and conference rooms to facilitate open sharing by informants without distraction or interruption, at locations agreed upon by researcher and informant. The interview guide was kept in a Word document electronically on the researcher’s password protected laptop, allowing
the researcher to add notes if needed while using the guide questions to ask the informants about their culturally based meanings, expressions, and practices related to ADs. Interviews were audio recorded using a voice recorder, for verbatim transcription into Microsoft Word and subsequent importing into NVivo 11, a qualitative data analysis software. Participants identified as “key informants” were asked to participate in one face-to-face interview and permission was asked to call to seek clarification and insight into initial responses, if needed. The interviews lasted from 60 to 90 minutes each.

**Instruments and Procedures for Data Collection.** This study utilized a semi-structured interview guide as the data collection tool, and the researcher personally interviewed each informant in person. The interview guide (Appendix C) was used to assess familial, traditional and cultural influencers, from a purposive sample with snowballing group of informants. Gatekeepers were be sought from researcher contacts among churches, community groups, and other gatherings and locations within the AA community. Introduction and validation of the researcher by the gatekeeper facilitated access to willing informants. Leininger’s *Stranger to Trusted Friend Enabler* (Appendix B) was used to guide the relationship between the researcher and both key and general informants. The semi-structured interview guide questions addressed topics regarding EOL planning, but also sought to spark conversation and revelations of inner feelings about death and dying. The interviews uncovered insight into beliefs, values, and life experiences or factors that influence decisions about personal care options at EOL. Data was collected about knowledge and understanding of EOL planning, and to determine if EOL planning is valued, sought, and a culturally congruent option among this population.

Along with recording the information provided by the informants, field notes were kept describing the environmental surroundings including the building and office location, condition,
climate, and any distractors related to the space, as well the body language, clothing, demeanor, etcetera of the informants were recorded in field notes also. Demographic forms (Appendix C) were completed by each key and general informant. Participant responses were recorded using a voice recorder and later transcribed verbatim for all informant interviews. Pertinent information like location of encounter, circumstances, time of day, if meeting was planned or spontaneous, and all appropriate participant information was also documented and kept in the researcher’s password protected electronic files. The remainder of the demographic data collection was gathered by way of a researcher created survey with demographics for age, gender, race/ethnicity, income, and marital status. These demographic variables are interval, ordinal, categorical, and nominal level variables, and allowed for additional categorization of the responses gathered from informants.

Protection of Human Subjects. Institutional Review Board (IRB) oversight was sought from Duquesne University prior to seeking informants for participation. Possible risks to study participants were considered minimal, but researcher prior training and informed consent procedures identified by IRB were strictly adhered to. Data collection and interactions with participants followed current ethical standards and procedures. Informed consent (Appendix D) regarding informant participation was communicated to potential participants, who were asked to sign the consent. Specific IRB and ethical standards addressed and adhered to were:

- participation by informants was voluntary;
- the study sought to gain new nursing knowledge with possible benefits that may help others;
- data collection was described including the survey procedure and estimated amount of time needed to gather data;
• risk as minimal but topics of the survey questions may bring to mind remembrances that are emotional or uncomfortable;
• informants had the right to withdraw from the study at any time even though they had given prior consent;
• interview data was labeled such that no participant identifying factors were included with the data, but identified only by a numbered code; further, data, the code, and demographic files were stored in locked drawers in the researcher’s office; electronic data was stored in the researcher’s personal password protected computer files;
• results reported only in aggregate format;
• participants were provided with the study results if they chose to;
• all data, demographic files, and codes will be deleted three years after completion of the study;
• and information was provided about whom to contact for questions about the research or participants’ rights related to the study.

Qualitative Data Analysis. Leininger’s four phases of qualitative data analysis were utilized to analyze the data from this study (Leininger, 2006b). The phases include: 1) Collecting and documenting raw data, 2) Identification of descriptors and categories according to domains of inquiry and research questions. Emic and etic data are coded for similarities and differences, 3) Identifying patterns/contextual analysis, discover saturation of ideas and recurrent patterns, and 4) Identifying themes and theoretical formulations and recommendations. Participants will be sought until data saturation is achieved. The researcher reviewed all data for accuracy and completeness, and kept comprehensive records of dates, times, participants, and thematic and categorical findings identified in the iterative process of coding, categorizing, and interpreting
data. Open coding using the line by line process and data associations provided a thorough assessment for clustering and compartmentalizing of data. Transcribed files, field notes, memos, observations, interviews, logs, and documents were imported into NVivo, the qualitative data management software, and were coded and analyzed for patterns, themes, and categories.

**Study Limitations.** Limitations of this study are that participants were volunteers via a convenience sample, as well were from a single region of the country. Frail or home bound participants and participants from non-urban areas were not sought, thus a sample from a different geographical area or other demographic could possibly have provided different data from the sample used here, therefore with different findings. However, findings did provide a rich, contextualized understanding of EOL cultural values, practices, and beliefs of the AA population sample accessed.
References


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Study Findings

Implementation of End of Life (EOL) advance care planning (ACP) promotes patient and family centered care. EOL ACP as defined by Koss and Baker, is “a process through which competent adults can discuss their healthcare goals and communicate their preferences about life-sustaining treatment in the event they are ever unable to make medical decisions for themselves” (2017, p. 2). EOL ACP honors the wishes of individuals and families, but if not documented, families and practitioners face complex decision making issues.

EOL ACP rates are low among the general population, and even lower among minorities. The largest disparity exists between African Americans (AA) at 17-24%, and White Americans (WA) at 30-45% (Garrido et al., 2014; Huang, Neuhaus, et al., 2016). This disparity causes undue personal, social, and financial hardship for AA patients and families (Rhodes et al., 2015). While nurses provide care and offer education to individuals and families at EOL, they may not be familiar with culturally influenced barriers to EOL ACP among AAs. When care wishes have not been communicated to family and healthcare providers, surrogate EOL ACP decision making for an incapacitated loved one can be stressful and difficult. Family member surrogates sometimes choose life-prolonging interventions having little potential of extending quality life for loved ones (Hendricks Sloan et al., 2016; Sanders et al., 2016). Understanding cultural care practices of the population being served is integral for providing culturally congruent nursing care (McFarland & Wehbe-Alamah, 2015). Further, two important care concepts define distinct and equally important care components; generic care consists of culturally learned lay and traditional care modalities, while professional care refers to formally learned knowledge and practice skills taught and used in professional care settings (Wehbe-Alamah, 2018). The DOI for
this ethnonursing study was generic and professional care meanings, beliefs, and practices related to EOL ACP of AAs living in the Midwestern U.S.

**Brief Review of Literature**

A comprehensive IR of the literature revealed multiple cultural care beliefs and characteristics of AAs that negatively impact utilization of EOL ACP (Collins, Zoucha, Lockhart, & Mixer, 2018) including: (a) moderators to personal autonomy including familial and communal decision making, (b) mistrust of the healthcare system, (c) low health literacy and level of education, (d) importance of religion and belief that life and death are in God’s hands, and (e) desire for aggressive life sustaining treatments at EOL. However, culture bound meanings, expressions, and traditions related to EOL ACP among AAs have not been sufficiently studied to identify how nursing and other providers can promote culturally congruent care within the parameters of AA values, beliefs and practices. This study sought to understand those culturally based meanings, expressions, and traditions impacting EOL ACP among AAs currently living in the Midwestern U.S. to improve care for patients and families.

**Theoretical Framework**

Leininger’s Theory of Culture Care Diversity and Universality (CCT) was the framework guiding this research (Leininger, 2006a). The theorist held that, “care [is] the essence of nursing” and culture and care are interdependent and intertwined; that culturally appropriate nursing care is “culturally meaningful, therapeutic, congruent, and safe for people of diverse and similar cultures” and is essential to human health, wellness, and survival (Leininger, 2006a, p. 4). Leininger introduced theory constructs *emic* care, “the local, indigenous, or insider’s cultural knowledge and view of specific phenomena” and *etic* care, “the outsider’s or stranger’s views and often health professionals’ views and the institutional knowledge of phenomena,” noting that
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nurses need to be aware of these two concepts of care and incorporate both in care provided to the patient (McFarland & Wehbe-Alamah, 2015, p. 4). Culture care is care that is meaningful, desired by, and congruent with the values, beliefs, and practices of the patient; therefore, it is not dictated by the nurse or healthcare community; human care distinguishes nursing’s role in helping people heal, deal with disabilities, and/or impending death (Leininger, 2006a; McFarland & Wehbe-Alamah, 2015).

Method

The Ethnonursing Method (EM) was designed by Leininger to use with the CCT to facilitate qualitative study of nursing phenomena, and fit with the tenets of the theory and principles of qualitative research methodology. The researcher, using EM principles (a) maintained an attitude of open discovery, active listening, and genuine learning, (b) actively participated and reflected with informants about their meanings of what was seen, heard, or experienced, (c) recorded the shared ideas and meanings, and (d) used the assistance of an experienced EM mentor. The researcher took copious field notes, documented interview settings and surroundings, and used Leininger’s Sunrise Enabler (Appendix A) as a cognitive map to “discover embedded and multiple factors” related to EOL ACP for AAs living in the Midwestern U.S. (McFarland, 2018, p. 47). Use of the Sunrise Enabler, a graphic depiction of influencers of an individual’s worldview, aided in defining the DOI as generic and professional care meanings, beliefs, and practices related to EOL ACP. The enabler includes technological, religious and philosophical, kinship and social, cultural values-beliefs-lifeways, biological, political and legal, economic, and education as factors that shape culture care expressions, patterns, and practices of patients and families (Wehbe-Alamah, 2018). Additionally, the Stranger to Trusted Friend
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*Enabler* (Appendix B), a descriptive guide of participant indicators, assisted the researcher to move from stranger to trusted friend, and thereby, obtain in-depth and accurate data.

The purpose of this study was to identify cultural values, beliefs, and traditions related to EOL ACP and decision making among AAs, and to disseminate findings to improve delivery of culturally congruent patient and family care in EOL situations. The DOI was explored using informant interviews to identify answers to the following research questions:

**Research Questions.**

1. What are the EOL and ACP cultural perspectives, beliefs, and practices among AAs living in the U.S.?
2. What are the culturally based meanings, expressions, and traditions related to ADs among AAs living in the U.S.?
3. What are nursing care practices that facilitate culturally congruent EOL ACP among AAs living in the U.S.?

**Informants**

Access and recruitment of informants was accomplished using “gatekeepers,” defined as leaders or those in authority among the study population, who are trusted and vouch for the researcher’s character and credibility (Wehbe-Alamah, 2018). The EM defines two types of informants: *key informants* are those that are most knowledgeable regarding the DOI of inquiry, and represent the emic/insider values, beliefs, and practices of the population; *general informants* may have less knowledge regarding the DOI, yet offer cultural insights helping the researcher recognize diversities and universalities in identifying patterns and themes abstracted from the data (McFarland & Wehbe-Alamah, 2015). Following approval from appropriate institutional review boards, initial informants were identified by three gatekeepers, with additional informants
added via snowballing as their family and friends contacted the researcher and volunteered. Informants were a voluntary convenience sample of adults 21 years and older who self-identified as AA, agreed to be interviewed by the researcher and provided written consent. After initial data review, informants were classified as *key* or *general* relative to their knowledge of the DOI. The EM prescribes that researchers seek 12-15 key and 24-30 general informants for identifying culture care phenomena in a larger scale study, however data saturation can happen with fewer informants, (McFarland & Wehbe-Alamah, 2015).

### Data Collection

The EM and the *Sunrise Enabler* guided the researcher in identifying care meanings about values, beliefs, and practices of individuals, families, and population groups (McFarland & Wehbe-Alamah, 2015). The contextual influencers of the *Sunrise Enabler* helped the researcher gain a holistic cultural assessment and tease out hidden and covert insights about the DOI. The researcher created a semi-structured interview guide using the rays of the *Sunrise Enabler* as an exemplar. Data collection took place over a seven month period via individual audio-recorded face-to-face interviews lasting 60-90 minutes each, using the semi-structured interview guide.

### Data Analysis

Concurrent data collection and analysis was completed using Leininger’s Four Phases of Data Analysis for evaluation and interpretation of results of this study (Wehbe-Alamah, 2018). In phase one, the researcher conducted informant interviews collecting data via electronic recording to preserve a verbatim record of informant data. The researcher documented descriptions of interview locations (university/library conference rooms, restaurants, golf club meeting rooms, and mall food courts) and observations of informants’ body language, demeanor, and comfort level sharing about the DOI also. De-identified interviews and field note data were
transcribed into text documents and entered into NVivo 11 qualitative research software. In phase two of analysis, data were coded and classified within the software into categories related to the DOI and research questions. Eighteen categories were identified using the constructs of the CCT. In phase three, categories were scrutinized for recurrent patterns of similar and diverse meanings related to informant values, beliefs, and practices with nine patterns emerging about the DOI. In the fourth and final phase of data analysis, interpretation and synthesis of the nine identified patterns resulted in three major themes related to the DOI.

**Evaluation of Qualitative Data**

Wehbe-Alamah (2018) describes six evaluative criteria for analysis of qualitative data, developed first by Lincoln and Guba (1985), then expanded by Leininger for use with the EM. The criteria are credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability. Credibility was established by asking informants for their thoughts and opinions, assuring them they could be candid and honest as all data would be reported only in aggregate. Informant quotes are traced to patterns and themes providing an audit trail that contributes to credibility. Confirmability was affirmed by key informants and reaffirmed by general informants as the researcher contacted several informants and sought feedback and clarification that the interpretation of data was accurate. Meaning-in-context was established as the researcher iteratively explored the interview data and field notes to explicate full and contextual meanings from data gathered. Recurrent patterning was substantiated as different informants shared similar and dependable patterns about the DOI. Saturation was assessed and achieved via iterative review of the data throughout data collection until subsequent interviews produced redundancy of information with no new meanings, experiences, or insights shared.
The goal of transferability of findings was achieved as findings of this study may be reasonably transferable to other similar contexts and populations.

Findings

The total number of study informants (N=21) was determined based on data saturation. The sample consisted of 18 female and three male informants, ranging in age from 32 to 87 years (M = 58.4). While key informants (n = 11) were all females ranging in age from 41 to 69 years (M = 57.2), the general informants (n = 10) were seven females and three males ranging from 32 to 87 years of age (M = 59.8). All key and general informants lived in the Saginaw Bay and Detroit Metropolitan regions of Michigan. Ethno-demographic details are outlined in Table 1.

Analysis of data from key and general informant interviews, including field notes and journal observations, resulted in identifying 18 categories from which nine patterns (Table 2) of similar and recurrent meanings emerged about phenomena related to the DOI. These patterns were further analyzed, synthesized, and interpreted with three themes abstracted.

Theme 1. Faith in God and belief in life after death influences EOL decision making.

This universal theme was resultant from informants worldview, and religious and cultural beliefs, and was supported by four care patterns and numerous descriptors including expressed faith in God and membership and/or attendance at a Protestant or Catholic Church, that faith in God helped them work through diverse family opinions about care issues for loved ones, and drawing on their faith to find peace and compromise. All informants indicated faith in God and that His control over length of life diminishes the importance of written EOL documents. One informant descriptive statement supporting this theme was:
I mean…the Lord gave us life, the Lord allows us to live, move, and have our beings in this particular time frame but there’s a season for everything. You know, it’s up to the Lord, however long He gives me in this life is what I have.

Patterns also identified that faith in God impacts every area of informants’ lives, individuals’ worldview, family and social structure, how individuals think about time of death, and decisions about documenting or verbalizing EOL ACP wishes. Another pattern emerged also supporting this theme; faith in God makes surrogate decision making for a loved one less stressful.

Supporting this pattern, a key informant shared about making EOL decisions for both her father and mother when each could not speak for themselves, stated:

Me and my two sisters, you know, we’re Christians, we love the Lord, and we know that His will is paramount. So, you know we’re the type of people that we come together, we pray about it, then go home and, meditate on it and you know, see what the Lord’s will is, and then we…we come back together. We make the decision, and ultimately it’s the Lord’s will anyhow. We can decide to do whatever, but whatever His will is, is what’s going to be done.

General informants confirmed a strong faith in God, and that length of life is in God’s control. Christian belief in life after death was a common theme with universal and diverse descriptors identified, including that some AAs believe they cannot participate in organ donation after death because they need their body to be “whole” for resurrection in the afterlife, also for many cremation is not an option. An informant descriptor affirming this belief was: “You know, there’s a myth in the black community that people feel that they have to go to heaven with their eyes, their nose, and fingernails and everything, otherwise they won’t be accepted by God.”

**Theme 2. Strong matriarchal structure of AA families impacts EOL decision making.**
Supporting this universal theme, there were five care patterns and many descriptors that reflected informants’ worldview, and religious and cultural beliefs. Support was identified from both key and general informant data as patterns emerged that trusting close relationships between grandmothers, mothers, and daughters foster family decision making as well as surrogate EOL decision making, and that communication of family issues is initiated and transmitted primarily among female family members. Male family members are informed about but not usually brought into the decision making conversation. Informant descriptors of this care pattern include the following: a female key informant referring to her siblings’ EOL ACP wishes stated,

I’m learning more about them and their wishes, and I think it’s important that I do because they both have sons, and I don’t know that their sons could be strong enough to make those kind of decisions for their…their moms.

A 66 year old female key informant whose mother was still alive stated,

Now I can tell you this, and I just told my mom this yesterday again to her because I know she’ll step in and give her opinion, so I said “Mom…I’ve already decided what I want and don’t want done. [My son] knows that, so don’t bug him.” This is because I know how my mother is. She will put her two cents in. And she is the matriarch of the family and people, my son, might feel he should have to do what she says. So I had to be real clear. “You don’t do what your grandmother wants. You don’t do what your Aunt wants. You remember what your mom told you.” And I wanted to give him the strength to be able to say no to his grandmother.

Data patterns indicated that EOL ACP wishes are communicated verbally to trusted female family members, and that if a Legal Will exists and/or funeral service wishes have been made known, it will be communicated to daughters, granddaughters and nieces. A general informant
speaking of how EOL decisions are made in his family stated “My family would look to the family member closest to them or the matriarch of the family.” A key informant speaking of her personal EOL ACP wishes discussed with her sisters (adult son was not part of the decision making) also support matriarchal family structure,

   Well, I have a verbal one [EOL ACP], and I have expressed that with my sisters, we have talked about end-of-life type of things...me and the two girls, we’ve had some serious discussion about it, so...they [sisters] know. My son knows it as well.

Other patterns identified that verbal communication of “general” EOL ACP wishes are spoken from grandmothers to mothers to daughters, and that elder AAs readily assign EOL decision making “specifics” to their female children, stating “you can make that decision for me when the time comes”. When an elderly AA has no daughter, a niece may be called on to carry-out “general” EOL wishes, and to make the “specific” decisions at the time needed.

   Theme 3. Fear of talking about death, and mistrust of the U.S. healthcare system are significant influencers for AAs documentation of EOL ACP wishes.

   Universal and diverse patterns supporting this universal theme include that communication of EOL ACP wishes among AAs is predominantly verbal, that insufficient education and understanding of EOL ACP documents negatively impact their use, and some AA individuals do not talk about death and dying thinking it may hasten EOL. As one key informant shared,

   I think that, it is probably across all races of people, but people don’t like to talk about death. So, because they think it’s, you know, morbid if I talk about it; it might happen, so they don’t wanna talk about it.

Further a general informant confirmed,
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Yeah…just like simple little things like, that “I don’t want to be cremated” or “I don’t want to go to a nursing home that’s not going to change me; they’re not going to take care of me,” “I don’t want to leave my house” …my grandmother refused to leave her home so my aunt had to move in with her to take care of her.

Of particular importance regarding mistrust of the healthcare system, an informant talking about EOL and organ donation stated “Leave me alone…leave me intact. Don’t do anything with my stuff. They [AA patients] don’t know what you’re going to do with their body parts, so there’s lack of trust.” Finally, another general informant stated,

I just don’t think the education has been there yet, for things to be in writing. But everybody talks about, you know, they say “I don’t want you to leave me lingering on, and if I’m not going to get any better, let me go. Don’t…don’t let me linger”.

Every family, I think, has had that verbal conversation.

Discussion

The purpose of this study was to identify culturally based meanings, expressions, and traditions of EOL ACP and decision making among AAs living in the Midwestern U.S., and disseminate findings to the nursing community to improve delivery of culturally congruent patient and family care. Key informants shared and general informants confirmed family practices related to EOL ACP how decisions are made, and how wishes are communicated. In teasing out meanings, expressions, and traditions related to EOL ACP and decision making, key informants shared that faith in God and His control over life and death is foundational to every part of their lives, and impacts how decisions are made and communicated within families. This finding is consistent with the literature about this population (Garrido et al., 2014; Huang, Neuhaus, et al., 2016; Koss & Baker, 2017; Rhodes et al., 2015). However, new findings
revealed in this study highlighted that faith in God and His control over length of life influences the importance and difficulty of EOL decision making, especially by surrogates. Informants shared that decision making about care at EOL is less stressful knowing that personal decisions do not determine the final outcome, because ultimately life and death are controlled by God. The literature highlighted a distinctive among AAs regarding patient autonomy and EOL ACP and decision making, reporting that this population may not ascribe to individual autonomy regarding EOL ACP, or that ACP conflicts with other cultural values (Giger et al., 2006; Rhodes et al., 2015; Waite et al., 2013; Wicher & Meeker, 2012). However, analyzing and interpreting data from this study concerning personal autonomy and EOL ACP decision making revealed that it is not a matter of advance planning being unimportant, but rather, AAs just place lesser value on EOL ACP, because their cultural values and beliefs of faith in God and His control over life and death is of greater importance.

Finding that many AA families have a strong matriarchal structure was confirmed in this study, including new information that family communication and decision making happens primarily among the female family members. This new information stands to inform future EOL studies among AAs.

Further findings revealed that the theme of fear of talking about death and mistrust of the U.S. healthcare system reinforces similar findings highlighted in the literature review (Ko & Lee, 2014; Koss & Baker, 2017; Rhodes et al., 2015; Wicher & Meeker, 2012). While fear of the healthcare system by AAs is not new knowledge, information synthesized from this study about fear of the healthcare system coupled with the recurrent pattern of maintaining the human body “whole” after death so that “they will be accepted by God” in the afterlife was not revealed in previous literature. This new knowledge informs nursing practice in provision of culturally
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congruent care regarding organ donation, and will inform future EOL studies among AAs particularly when incorporating EOL planning that might include organ donation.

Finally, previous studies found that educational attainment was positively related to having completed documented EOL ACP wishes (Lovell & Yates, 2014; Rao et al., 2014; Waite et al., 2013); however this study’s informants had much higher than average levels of education (67% with baccalaureate degree or higher, and 24% with doctoral degrees) yet the percentage of informants with documented EOL ACP wishes was still low at only 19%, within the range of 17-24% for all AAs in the U.S. as reported by Collins et al. (2018).

Implications for Nursing Research and Practice

Research. Findings from this research add to the body of knowledge for the discipline of nursing, and contribute to greater understanding of the disparity in prevalence of EOL ACP and documentation among AAs in the Midwestern U.S. Nurses caring for AA patients and families, knowledgeable about the cultural distinctives of (a) faith in God and His control over length of life, (b) the strong matriarchal structure of many AA families and that family communication happens among female family members, and (c) the belief in maintaining the body whole and intact even after death, will improve provision of culturally congruent nursing care. Additional EOL ACP research building on the findings of this study needs to be conducted to gain additional insight in providing care for AA patients and families.

Practice: Using the CCT and EM action modes.

The CCT and EM include three culture care decision and action modes based on identified data the researcher can use for providing culturally congruent care. Culture care preservation and/or maintenance refers to those “enabling professional acts or decisions that help cultures to retain, preserve, or maintain beneficial care beliefs and values or to face
handicaps and death” (McFarland & Wehbe-Alamah, 2015, p. 16). Therefore findings of this study can be used clinically to preserve and/or maintain culturally congruent care for AA patients as nurses and other healthcare providers are encouraged to assess for and include a desired faith component in the plan of care. While having a strong faith in God is not descriptive of every AA patient, cultural assessment asking about the patient’s faith beliefs will quickly provide that information to the nurse. Considering the importance and strong faith of many AAs, culturally congruent EOL nursing care must include provision for faith, prayer, and belief that God is in control of life and death.

*Culture care accommodation and/or negotiation* refer to those professional “care actions or decisions that help cultures adapt to or negotiate with others for culturally congruent safe and effective care for their health, well-being, or to deal with illness or dying” (McFarland & Wehbe-Alamah, 2015, p. 16). The identified universal care pattern of females verbally sharing, as well as older males sharing with female family members their EOL ACP wishes was identified, however, younger males should also be encouraged to share EOL ACP wishes with family members so wishes can be honored should early death occur, and to ease anxiety about fear of death.

*Culture care repatterning and/or restructuring* refer to “professional actions and mutual decisions that help people to reorder, change, modify, or restructure their lifeways and institutions for better healthcare patterns, practices or outcomes” (McFarland & Wehbe-Alamah, 2015, p. 16). Nurses are encouraged to educate and assure AAs that written EOL ACP documents are beneficial and can help them achieve desires and goals for EOL care for themselves or for a loved one. Further, nurses should help patients understand EOL documents
can be changed at any time to accommodate changing EOL wishes, and that having these documents in place does not negatively impact the quality of care they will receive.

Limitations

Despite the value of the study findings, there are recognizable limitations. Findings from a volunteer convenience sample may not be representative of the population as a whole. Further, transferability of findings to other minority cultures may not be applicable due to the specificity of AA culture bound identified values, beliefs and practices.

Conclusion

This study focused on understanding the disparity in EOL ACP among AAs living in the Midwestern U.S. and the cultural factors that impact that disparity. In AA culture, many values, beliefs, and traditions surrounding EOL ACP and decision making are embedded in religious and faith beliefs, family and social structure, identified fear of talking about death and general mistrust of the healthcare system. To provide holistic culturally congruent care, nurses and healthcare providers must be sensitive to the cultural care factors identified in this study, and incorporate these culture care generic (emic) constructs into the professional (etic) plan of care. This knowledge about the DOI will improve the patient care experience for AAs and their families facing EOL situations, and adds to the evolving body of transcultural nursing care knowledge related to culture care of AAs at EOL.
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doi:10.1177/0898264312449185


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## Table 3

**Informant Demographics (N = 21)**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age by decade</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30s</td>
<td>1</td>
<td>5.0</td>
</tr>
<tr>
<td>40s</td>
<td>5</td>
<td>23.8</td>
</tr>
<tr>
<td>50s</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td>60s</td>
<td>10</td>
<td>47.6</td>
</tr>
<tr>
<td>70s</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>80s</td>
<td>1</td>
<td>5.0</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Female</td>
<td>18</td>
<td>85.7</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
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<td></td>
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<tr>
<td>Non-Denominational</td>
<td>9</td>
<td>42.9</td>
</tr>
<tr>
<td>Baptist</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>Catholic</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Lutheran</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Adventist</td>
<td>1</td>
<td>5.0</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
<td>42.9</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td>Widowed</td>
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<td>5.0</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td></td>
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<tr>
<td>High School</td>
<td>4</td>
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<tr>
<td>Associate Degree</td>
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<td>14.3</td>
</tr>
<tr>
<td>Baccalaureate Degree</td>
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</tr>
<tr>
<td>Master’s Degree</td>
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<td>0.0</td>
</tr>
<tr>
<td>Doctoral</td>
<td>5</td>
<td>23.8</td>
</tr>
</tbody>
</table>
## CULTURAL ASPECTS OF END OF LIFE ADVANCE CARE

### Table 4

*Themes and Associated Patterns*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Associated Patterns</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Faith in God and belief in life after death influences EOL decision making.</td>
<td>1. Strong faith in God and He determines length of life</td>
</tr>
<tr>
<td></td>
<td>2. Faith in God impacts informants’ lives, individuals’ worldview, family and social structure, how individuals think about time of death, and decisions about documenting or verbalizing EOL ACP care wishes</td>
</tr>
<tr>
<td></td>
<td>3. Faith in God makes surrogate decision making less stressful knowing God is ultimately in control</td>
</tr>
<tr>
<td>2. A strong matriarchal structure of AA families impacts EOL decision making.</td>
<td>1. Many AA households are matriarchal</td>
</tr>
<tr>
<td></td>
<td>2. Communication travels among females in the family</td>
</tr>
<tr>
<td></td>
<td>3. EOL wishes are communicated verbally to trusted family members but are seldom written</td>
</tr>
<tr>
<td></td>
<td>4. An unofficial Will may exist but usually will be in a personal lockbox or other safe location in the home</td>
</tr>
<tr>
<td>3. Fear of talking about death, and mistrust of the U.S. healthcare system are significant influencers for AAs’ documentation of EOL wishes.</td>
<td>1. Fear of talking about death</td>
</tr>
<tr>
<td></td>
<td>2. Mistrust of the healthcare system and of family members not honoring EOL wishes</td>
</tr>
</tbody>
</table>
Appendix A

The purpose of this Enabler is to facilitate the researcher (or it can be used by a clinician) to move from mainly a distrusted stranger to a trusted friend in order to obtain authentic, credible, and dependable data (or establish favorable relationships as a clinician). The user assesses oneself by reflecting on the indicators while moving from stranger to trusted friend. These are dynamic indicators from cultures.

<table>
<thead>
<tr>
<th>Indicators of Stranger (Largely etic or outsider’s view)</th>
<th>Dates Noted</th>
<th>Indicators of a Trusted Friend (Largely emic or insider’s view)</th>
<th>Dates Noted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informant(s) or people are:</td>
<td></td>
<td>Informant(s) or people are:</td>
<td></td>
</tr>
<tr>
<td>1. Active to protect self and others.</td>
<td></td>
<td>1. Less active to protect self.</td>
<td></td>
</tr>
<tr>
<td>They are <em>gatekeepers</em> and guard against outside intrusions. Suspicious and questioning</td>
<td></td>
<td>More trusting of researchers (their <em>gatekeeping is down or less</em>). Less suspicious and less questioning of researcher.</td>
<td></td>
</tr>
<tr>
<td>2. Actively watch and attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.</td>
<td></td>
<td>Less watching the researcher’s words and actions. More signs of trusting and accepting a new friend.</td>
<td></td>
</tr>
<tr>
<td>3. Skeptical about the researcher’s motives and work. May question how findings will be used by the researcher or stranger.</td>
<td></td>
<td>Less questioning of the researcher’s motives, work and behavior. Signs of working with and helping the researcher as a friend.</td>
<td></td>
</tr>
<tr>
<td>4. Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values, and beliefs. Dislikes probing by the researcher or stranger.</td>
<td></td>
<td>Willing to share cultural secrets and private world information and experiences. Offers most local views, values, and interpretations spontaneously or without probes.</td>
<td></td>
</tr>
<tr>
<td>5. Uncomfortable to become a friend or to confide in stranger. May come late, be absent, and withdraw at times from researcher.</td>
<td></td>
<td>Signs of being comfortable and enjoying friends and a sharing relationship. Gives presence, on time, and gives evidence of being a genuine friend.</td>
<td></td>
</tr>
<tr>
<td>6. Tends to offer inaccurate data.</td>
<td></td>
<td>6. Wants research <em>truths</em> to be accurate regarding beliefs, people, values, and lifeways. Explains and interprets <em>emic</em> ideas so researcher has accurate data</td>
<td></td>
</tr>
<tr>
<td>Modifies <em>truths</em> to protect self, family, community, and cultural lifeways. <em>Emic</em> values, beliefs and practices are not shared spontaneously</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Appendix C

### Cultural Aspects of End of Life Advance Care

**Open Inquiry Guide - Key and General Informants**

<table>
<thead>
<tr>
<th><strong>ETNODEMOGRAPHICS</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td>Places lived:</td>
</tr>
<tr>
<td>Informant #:</td>
<td>Years of education:</td>
</tr>
<tr>
<td>Gender:</td>
<td>Occupation/Employment status:</td>
</tr>
<tr>
<td>Age:</td>
<td>Date of contact:</td>
</tr>
<tr>
<td>Race/Ethnicity:</td>
<td>Religious affiliation:</td>
</tr>
<tr>
<td>Marital status:</td>
<td>Annual income:</td>
</tr>
<tr>
<td>Place of birth:</td>
<td>Healthcare insurance:</td>
</tr>
<tr>
<td>Years in current city:</td>
<td>Number and age of children:</td>
</tr>
</tbody>
</table>

### OPEN-ENDED QUESTIONS

#### Care
1. I am interested in learning what you believe about end of life care; please tell me what care means to you, and how end of life care is similar or different.
2. Please tell me about what happens in your family when you or a family member is ill.
3. Please tell me about the healthcare decision making process if you or someone in your family were near end of life.

#### Health and Well Being
1. I am interested in learning about your health; would you tell me about your health?
2. What does *Good Health* mean to you?
3. Tell me about the care you receive from nurses and healthcare providers.
4. What do you personally do to maintain good health:
   - describe certain foods, activities, or medicines that you believe keep you healthy
   - any home remedies you use
   - use of incense, candles, poultices, etc.?
5. If you or a family member were experiencing a life-limiting illness or injury and could not personally tell the doctor/nurse/caregiver what you/they would like, describe how decisions about your/their care would be made.
6. What value, if any, would you or your family place on thinking about or planning for a time when you might be dying?
7. Talk about if parents or other relatives have told you what they wanted done medically if they are near death? In your family, who makes decisions about medical care/procedures?
8. Please tell me what you know about end of life advance care planning.

#### Environmental Culture
1. Please tell me about your family or people that you live with.
2. Please tell me about your house or apartment where you live.
3. Please describe your neighborhood including the people and the environment.

**Educational Factors**
1. Tell me about any difficulty you might have had understanding things your doctor, nurse, or other healthcare provider ask you about when you see them?
2. If there are things you don’t understand that your healthcare provider says, describe how you ask for clarification or tell them you don’t understand?

**Economic Factors**
1. Please describe if economics has impacted decision making about your healthcare.

**Kinship/Social Factors**
1. When it comes to healthcare and making decisions about healthcare, are family members involved? Please describe.
2. Is there anyone outside of family members who is involved in making healthcare decisions for you or other family members?

**Religious Factors**
1. Tell me what part religion/spirituality plays in your life?
2. Please tell me how your religious beliefs impact your views about health, length of life, and time of death.
3. Do your spiritual beliefs influence your ability to plan for end of life healthcare wishes, if so how?
4. Do you or your family have spiritual beliefs that would influence what procedures or medical interventions could be done to keep you alive, and if so please describe.

**Cultural Factors**
1. Please tell me what you understand about end of life advance care planning?
2. Have you thought about what medical procedures you want or don’t want when that inevitable time comes in your life? Please describe.
3. Tell me about any responsibility you have had to make decisions about healthcare for a loved one?

**Summary Question**
1. Is there anything else you want to tell me about?
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE:
Cultural Aspects of End of Life Advance Care Planning for African Americans

INVESTIGATOR:
John W. Collins, MS, RN
Duquesne University School of Nursing

ADVISOR:
Rick Zoucha, PhD, PMHCNS-BC, CTN-A, FAAN
Joseph A. Lauritis, C.S.Sp. Endowed Chair for Teaching and Technology
Professor and Chair of Advanced Role and PhD Programs

SOURCE OF SUPPORT:
This study is being performed as partial fulfillment of the requirements for the PhD degree at Duquesne University School of Nursing.

PURPOSE:
You are being asked to participate in a research project that seeks to investigate values, beliefs, and practices of African Americans at end of life.

In order to qualify for participation, you must be: an English speaking African American adult male of female resident of the United States, 21 years of age and older, who self-reports having not been diagnosed with a life-threatening illness or disease, who agree to complete the qualitative semi structured interview with the researcher, and the personal demographics survey.

PROCEDURES:
To participate in this study, you will be asked to provide responses to questions about your demographic information. In addition, you will be asked to allow me to interview you. The interviewer will ask you to answer questions about the culturally based meanings, expressions, and practices related to ADs among AAs in the US. Interview questions will include talking about your family, home, and environment. Also, questions will include asking about your education, economic, kinship and social factors, spirituality and religious beliefs and practices, as well as cultural values and traditions you, your family and friends hold about end of life, dying, and planning for that time. Interviews will be conducted individually in private offices or conference rooms, or a place of your choosing and will be audio recorded with your permission,
then later transcribed into a word document. You may be contacted for up to two additional
interviews after the first interview if clarification is needed on any of the initial responses.
Interviews should last no longer than approximately 60 minutes. These are the only requests that
will be made of you.

RISKS AND BENEFITS:
There are minimal risks associated with participating in this study, but no greater than those
encountered in everyday life. There may be no personal benefit from your participation but the
knowledge received may be of value to humanity, and insights gained may guide changes in
nursing healthcare delivery in the future. Knowledge gained from all participants’ responses will
be aggregated and summary information may be published in journals and periodicals.

COMPENSATION:
There will be no compensation for participating in this study, and participation in this project
will require no monetary cost to you.

CONFIDENTIALITY:
Your participation in this study and any personal information that you provide will be kept
confidential at all times and to every extent possible.

Your name will never appear on any survey or research instruments. All written and electronic
forms and study materials will be kept secure. Your response(s) will only appear in aggregated
qualitative summaries. Any study materials with personal identifying information will be
maintained for three years after the completion of the research and then destroyed.

Audio recordings of the interviews will be kept on password protected computers in the research
office, and will be deleted after data analysis, but not later than three years after completion of
the study.

RIGHT TO WITHDRAW:
You are under no obligation to participate in this study. Your participation is voluntary. You are
free to withdraw your consent to participate at any time. Refusal to participate or withdrawal of
your consent or discontinued participation in the study will not result in any penalty or loss of
benefits or rights to which you might otherwise be entitled. The principal investigator may at his
discretion remove you from the study for any of a number of reasons. In such an event, you will
not suffer any penalty or loss of benefits or rights which you might otherwise be entitled.

SUMMARY OF RESULTS:
A summary of the results of this research will be supplied to you, at no cost, upon request.
VOLUNTARY CONSENT:

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may call the Duquesne University Institutional Review Board, at 412.396.1886.

___________________________________  __________________
Participant’s Signature               Date

___________________________________  __________________
Researcher’s Signature                Date