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Understanding End-of-Life Decision-Making Terminology Among African Americans

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Abstract

The purpose of the current study was to examine understanding of end-of-life (EOL) decision-making terminology among family caregivers of African American older adults with dementia. This qualitative descriptive study was part of a larger mixed-methods study from which a subset of caregivers ($n = 18$) completed interviews. Data were analyzed using descriptive statistics and content analyses guided by methods of qualitative analysis. Caregiver interpretation of EOL decision-making terminology varied between associations before and/or after death. EOL decision making was most often a family decision, based on past experiences, and included reliance on resources such as faith or spirituality and health care providers. Patients and families attach meaning to health care terms that should be aligned with health care providers' understanding of those terms. Results provide insight to improve EOL decision making in this population via tailored interventions for patients, families, and health care providers.

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Regardless of prognosis, African American individuals do not prepare for life's end, and are more likely than Caucasian individuals to request life-sustaining treatment measures (Allen, Hilgeman, & Allen, 2011; Carr, 2012; Daaleman, Emmett, Dobbs, & Williams, 2008; Kelley et al., 2011; Nicholas, Langa, Iwashyna, & Weir, 2011; Wicher & Meeker, 2012; Winter, Dennis, & Parker, 2007). African American individuals use the highest amount of intensive care and lowest amount of hospice care at the end of life, compared to other races (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009). As such, African American older adults with dementia are at an increased risk of facing the end of life without advance care plans and are vulnerable to receiving unwanted interventions (Phipps, Braitman, True, Harris, & Tester, 2003). This lack of advance care plans often leaves caregivers struggling to make surrogate end-of-life (EOL) decisions.

Multiple factors influence advance care planning (i.e., formal, informal, or no advance care plans) for African American individuals with dementia and/or their surrogates or family caregivers (Walker, 2013). Among these, the following factors are noteworthy: familial and individual belief systems (Campbell & Ash, 2007; Mazanec, Daly, & Townsend, 2010), socialization and culture (Bullock, 2011; Johnson, Kuchibhatla, & Tulskey, 2009), spirituality and/or religion (Carr, 2012; Nath, Hirschman, Lewis, & Strumpf, 2008), and events in history (e.g., the Tuskegee Syphilis Study and Henrietta "HeLa Cells" Lacks Story) that contribute to mistrust of U.S. health care systems (Campbell & Ash, 2007; Mazanec et al., 2010). These factors make it increasingly important for health care providers to approach all patients as individuals, without assumptions or judgment regarding their care choices (Institute of Medicine [IOM], 2015).

Regardless of one's cultural background, death is a shared human experience often discussed with reluctance (Gire, 2014). The importance of care delivery that is culturally sensitive to the needs of patients and families cannot be overstated. Care provided by nurses, physicians, and the remainder of the health care team must be delivered without undue biases that can potentially inhibit equity of health care delivery. Medical systems, viewed as cultural systems, stress illness as culture and caregiving as a moral experience (Kleinman, 1978, 2012). Morals and values are rooted in cultural identification.

Transcultural nursing care offers awareness of covert cultural trends that influence beliefs, values, and practices as it relates to gender, race, age, and class, and impacts patient care (Leininger, 1997). The Culture Care Theory developed by nurse anthropologist Dr.

Madeleine Leininger, known for its holistic but culture-specific focus to discover meaningful care to diverse cultures, is integral to transcultural nursing. Included in this anthropologic perspective is the use of comparative care to influence nursing practice that is inclusive of care near the end of life. From this perspective, factors related to cultural stress that are counter-therapeutic to patients and families' well-being can be identified. According to this theory, culture care concepts, meanings, expressions, processes, patterns, and structural forms vary transculturally, with differences and commonalities (Leininger, 2002).

Dementia is a life-limiting illness that affects decision making in older adults, increasing the need for surrogate decision making (Braun, Beyth, Ford, & McCullough, 2008; Campbell & Ash, 2007). Few studies exist that focus on the EOL experience for individuals with dementia and their families (Caron, Griffith, & Arcand, 2005). African American older adults are two times more likely to develop dementia than Caucasian individuals (Alzheimer's Association, 2016). Notably, African American individuals account for 13% of family care-givers in the United States (Alzheimer's Association, n.d.). The number of African American individuals caring for relatives with dementia is greater than that of Caucasian individuals in similar situations (Alzheimer's Association, n.d.).

Few reports and landmark studies exist that describe the state of the science on EOL decision making for adults in the United States (Connors et al., 1995; IOM, 1997; Library of Congress, 1990). Most recent is the 2015 IOM consensus report, "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life," which calls for improvements in quality of life through the end of life. This report highlights the need for culturally relevant, person- and family-centered EOL care, with a focus on those who are mentally incapacitated. Further, the 2016 National Academies of Sciences, Engineering, and Medicine (NASEM) report, "Families Caring for an Aging America," sheds light on the increasing diversity of older adults and their families, and the need to adequately address the needs and values of these caregivers. Terminology matters when discussing EOL issues (IOM, 2015), particularly among Black individuals and, more specifically, understanding of health care terminology is important as it relates to EOL planning to ensure their understanding (Moss & Williams, 2014).

The purpose of the current qualitative descriptive study was to examine understanding of EOL decision-making terminology among family caregivers of African American older adults with dementia. The terms African American and Black individuals are used interchangeably to include those of sub-Saharan African or Caribbean heritage (Rastogi, Johnson, Hoeffel, & Drewery, 2011) acclimated through socialization in the United States from birth or migration.

Conceptual Framework

Surrogate decision making is a difficult psychological task (Dionne-Odom & Bakitas, 2012). The current study was guided by the Framework of EOL Decision Making in Dementia by Family Caregivers, derived from Caron et al. (2005). This theory of human action was developed using grounded theory methods of constant comparison and dimensional analysis of EOL decision-making perspectives of dementia family caregivers (Caron et al., 2005).

The Framework of EOL Decision Making in Dementia by Family Caregivers focuses on two dimensions from Caron et al.'s (2005) work: (a) dimensions associated with the older adult with dementia, and (b) dimensions associated with the caregiver. Primary antecedents are categorized as either of these dimensions. Older adult dimensions include demographics, cultural belief system, general health status, reported stage of the disease, past EOL experiences, length of time since cognitive impairment, wishes for end of life (if any), institutionalization status, and health-related quality of life. Caregiver dimensions include demographics, cultural belief system, relationship to the individual with dementia, length of time in caregiving role, EOL wishes for self, past EOL experiences, self-efficacy for surrogate decision making, and health-related quality of life. The current study examined how components of these dimensions are influential to caregiver understanding of EOL decision-making terminology. The literature supports the use of this framework for EOL decision making, as it provides a basis for improving plans for more effective health care outcomes inclusive of the provision of family-centered care (Wiegand, Grant, Cheon, & Gergis, 2013).

Method

The current study used a qualitative descriptive design and was part of a larger, mixed-methods study. Participants were a subset of care-givers who participated in the larger study. Throughout the current study, family caregivers were considered the surrogate or proxy decision makers for individuals with dementia, and as such, the terms are often interchanged. Institutional Review Board (IRB) approval was obtained prior to conducting the study.

Recruitment and Sample

Participants, African American caregivers of African American older adults with dementia, were recruited from communities and facilities, such as the Programs of All-Inclusive Care for the Elderly (PACE), across a southeastern state. Additional recruitment venues included community events/health fairs, as well as referral sampling methods in the community (e.g., personal referrals). After initial approach, arrangements were made with each participant for a date, time, and location to conduct data collection. Eligibility criteria for the family caregiver were: self-identified as African American/Black; at least age 21; an assigned caregiver to an African American/Black older adult with dementia (as reported by the family caregiver) 55 or older at the time of study enrollment; and able to read, speak, and understand the English language. Exclusion criteria were: any form of cognitive impairment as determined via self-report during the screening and consenting process, being acutely hospitalized with a life-threatening illness, and actively dying. The minimum age limit of 55 years for the care recipient was chosen because this is the age requirement for participation in PACE (Centers for Medicare & Medicaid Services, n.d.). Each family caregiver was given a \$10 gift card for participating in the study.

After completing the surveys for the larger study at the chosen location, those who agreed to participate in the current study completed interviews. Participants were purposively included in interviews based on inclusion of a diverse sample of those whose care recipient was and

was not enrolled in a PACE program to ensure both perspectives were captured. Once data saturation was achieved, no additional interviews were conducted; however, recruitment for the larger study continued (Guest, Bunce, & Johnson, 2006). Based on research conducted by Guest et al. (2006), it was estimated that approximately 12 to 20 participants would be required to achieve data saturation-the point at which no new themes or information emerged from data collected. A convenience sample of African American dementia caregivers (N = 18) participated in the current study.

Data Collection and Analysis

Each family caregiver represented one care recipient who was an older adult with dementia. Data were collected at a location chosen by the caregiver, which was most often the caregiver's home or a nearby coffee shop. One interviewer (K.O.M.) solely conducted each interview, which enabled familiarity with and closeness to the data, as well as understanding of the context in which data were collected. The concept of data saturation was used to determine when to close the study to new participants. An interview guide (Patton, 2015) was developed to include interview questions focused on surrogate decision making, and understanding of terms related to EOL and quality of life. Interviews were audiorecorded and transcribed verbatim using an independent, IRB-approved vendor. Based on experiences with the initial interviews, the interviewer became aware of the need to restate questions when indicated to reflect the ability of the participant to understand the questions being asked. For example, caregivers were asked if their understanding of the term "end of life" refers to "before death," "after death," or "both." This additional question helped reveal pivotal information regarding their understanding.

Descriptive statistics were conducted on the demographic data using SPSS version 23. Interview transcripts were re-verified along with the audiorecorded interviews to make corrections and/or clarify misunderstood words. Once transcripts were verified, transcriptions and audio were uploaded into Dedoose ®version 6.1.18 for further analysis. Dedoose is a web-based application for managing, analyzing, and presenting qualitative and mixed-methods research data. Once all data were verified, digital recordings on both devices were erased.

Data analysis was iterative. Content and thematic analyses were used initially to examine participants' thoughts, feelings, and attitudes-foundational topics in naturalistic inquiry (Sandelowski, 2000). These analyses were informed by Miles, Huberman, and Saldana's (2014) methods for qualitative analysis. Informational redundancy and reflexivity were used to enhance trustworthiness of the findings (Chiovitti & Piran, 2003; Pyett, 2003). As described by Miles et al. (2014), data were reduced and displayed in different visual formats and conclusions were verified.

Codes were developed deductively from constructs and variables the researchers brought to the study, and inductively, emerging from data (Miles et al., 2014). Three cycles of coding were conducted. The first cycle was conducted using Dedoose with descriptive coding and assigning labels to data by summarizing with a word or short phrase (Miles et al., 2014). Deductive coding was also used, as some codes were predetermined based on the conceptual

framework used in the study (Miles et al., 2014). Still other codes emerged from data, and these were coded as transcripts were analyzed.

The second round of coding was more explanatory in nature and was conducted using holistic coding methods in which larger units of data were grouped, as this assisted with contextual understanding (Miles et al., 2014). In addition to these methods, analytic memos were made in Dedoose to remind the researchers of details, such as the context surrounding data extracted (e.g., when a participant was being sarcastic, when emotions such as sadness or crying were observed).

For the third round of coding, data were printed onto hard copy and reanalyzed using paper, pens, and highlighters. Analytic memos were transferred onto the hard copies as necessary. With each round of coding, codes became more refined and were rearranged and reclassified into themes (Saldana, 2016). Research team members were consulted for verification of these analyses. Member checking with two participants was used to verify that the results of the analysis were true (Lincoln & Guba, 1985; Pyett, 2003). A letter outlining study results was shared with key participants beforehand to ensure ease of understanding the results prior to dissemination of the letter to all participants. Following data analysis, a letter of thanks was mailed to each participant and included study results in laymen's terms to help ensure understanding.

Results

Caregiver Characteristics

Of 18 participants, caregivers were mostly female (94.4%) and most often daughters (66.7%) caring for a parent with dementia. Participants caring for a spouse represented 16.7% of the sample. Other caregivers included a sister, son, and cousin of the loved one with dementia. The most common marital status was married (44.4%), followed by single (27.8%), separated or divorced (22.2%), and widowed (5.6%).

Caregivers' mean age was 62 years (range = 46 to 80 years). Education level ranged from eighth grade through doctoral degree, with five (27.8%) having completed high school, eight (44.4%) having completed 1 to 4 years of college, and five (27.8%) having completed some postgraduate studies or postgraduate degree. Eight (44.4%) caregivers earned $\leq$ \$25,000 and 10 (55.6%) earned $>$ \$25,000. Five (27.8%) had been caregivers for an older adult for $<$ 5 years, whereas 12 (66.7%) had provided care for 5 to 10 years, and one (5.5%) had been a caregiver for 18 years.

Care Recipient Characteristics

Most care recipients were female (77.8%). Ages ranged from 62 to 96 years. Most forms of dementia were self-reported as unknown/unclassified (55.6%). Time since diagnosis of dementia was 0.17 to 13 years. Less than one half of care recipients were enrolled in PACE (44.4%). Only four (22.2%) care recipients were living in institutional settings. Results are reported under four major themes: (a) Meaning of EOL Terminology , (b) Advance Directive Versus Living Will , (c) Understanding of Quality of Life , and (d) EOL Decision Making .

Meaning of End-of-Life Terminology

Both. My prayer is that my mom will remain in her home.... I don't want her to have to go into a hospital and suffer.... I really don't want her to go to a nursing home and live. And after death is not a problem because [of] insurance and a lot of things are, they are paid for....

For this caregiver, the focus was on preparation prior to and following death.

Responses to the meaning of "end of life" often referenced burial insurance or burial plot payment as security, or funeral plans. One caregiver answered, "Both, because of funeral arrangements and all that sort of thing."

There were differences among caregivers who admitted that they did not like to talk about death versus those who were content to say that plans were already in place, either formal or informal. Most caregivers were comfortable talking about death. Caregivers of care recipients enrolled in PACE often also had an in-depth understanding of the meaning of EOL terminology, anticipating health care providers within the program focusing on health care wishes before death. Throughout the interviews with caregivers, it appeared that their expectations were aligned with their understanding of their loved one's condition. Although they were not ready for them to die, they confidently expressed their care recipients' health care wishes toward the end of life.

Advance Directive Versus Living Will

The terms "advance directive" and "living will" were associated with "putting wants/wishes in writing," whether health care-related. Caregivers admitted that they were confused about the differences between the terms. Participants expressed difficulty differentiating between these two documents. Caregivers were able to accurately state the purpose of either an advance directive or living will, but not both. The term "living will" was often confused with a "will" that typically assigns the inheritance of personal property at death. One caregiver said, "But the living will just kind of makes sure the families don't get to fighting about possessions, or 'I want this, or I want that'." All caregivers identified both terms as referencing written documents and were in agreement that these were a good thing to have to make one's wishes known.

Understanding of Quality of Life

When caregivers described their understanding of the meaning of "quality of life," codes that emerged primarily included reflections on past activities that evoked feelings of "happiness or contentment" by their loved ones and preservation of "dignity and respect." When caregivers were asked to describe their loved ones' quality of life, responses varied from "poor" or "diminished" to "good" or "excellent." One caregiver noted, "I would say she is in a good place...her quality of life is good." Interestingly, some caregivers used the same terms to describe their own quality of life.

End-of-Life Decision Making

EOL decisions made by caregivers were not autonomous (i.e., independent acts); family involvement was evident. Decisions were made in collaboration with either care recipients (in instances when they were able to contribute), loved ones (e.g., children, grandchildren, siblings), and/or health care providers. As a result, these decisions seemed to be made over time through appropriate consultations with key stakeholders (i.e., the care recipient when possible), other family members, health care providers, and God.

Family involvement in care of this group of African American older adults with dementia was significant. A change in behavior or health status in the care recipient was the most frequent indicator that prompted the need for caregiver decision making. One participant explained, "We [the family] put our heads together and make a decision." Conversations were often held with other family members and included the care recipient, particularly prior to the recipient's memory loss. Even in instances where memory loss was evident and the care recipient provided input in decisions, caregivers often provided opportunities for his/her choices to be considered. For example, one caregiver noted, "She has already expressed to me [that] she does not want to prolong her life by being on a ventilator." In such an instance, verbal plans were most significant, as prior conversation was an important factor that emerged as a key influencer in EOL decision making. Such prior conversations with an older adult with dementia mattered, especially when there was no decision for desired health care toward the end of life already documented.

Care recipients' past experiences with loved ones dictated how they felt about what they wanted for themselves, and affected caregivers' decision-making processes. For example, one caregiver recounted the death experience of a care recipient's sibling, with an indication that the care recipient "did not want to suffer like she did." In this instance, when the care recipient had previously been in the caregiving role, she gained firsthand experience of the difficulties of caregiving for someone near the end of life. As a result, the care recipient was able to express (prior to memory loss) that she did not want to choose the same fate.

Care recipients' and caregivers' past and professional experiences were also influential in the decision-making process. During interviews, caregivers sometimes made direct reference to care recipients' past experiences that shaped the way they would choose to oversee their own wishes regarding EOL decisions. Several participants came from professional health care backgrounds, and some had a strong educational background or high family income. For example, in reference to EOL planning, one caregiver stated, "She's already done that [completed an advance directive] so that made it a lot easier because, well, she always told us [while we were growing up] about her being a nurse herself [and] what she wanted..." In this instance, the care recipient's background influenced responses to questions posed by the researcher related to confidence toward the decision-making process, and clearly framed his/her thinking about health care toward the end of life, as these caregivers were most comfortable about discussing end of life.

You know that at some point you will be leaving this earth, so therefore, you have [some] time. Actually, it's a good thing. Some people don't see it that way. But if you have time to

plan, that's good because some people just leave, just like that, without saying goodbye. You have time to make amends and a whole lot of other things.

She further described her care recipient as "a praying woman" prior to being diagnosed with dementia. The caregiver's reference to preparation for death became clearer as she described her care recipient no longer "suffering" with dementia. This caregiver also described the time before death as preparation to "reflect [and] rejuvenate," and make amends with others. She went on to say, "And after you have done all that you can, [you can] say 'God, I'm ready'." This conversation reiterated the role of faith/spirituality when discussing EOL. It was clear from the interviews that regardless of one's belief system, each individual was likely to have a perception of what happens after death.

Caregivers provided evidence that they rely heavily on health care providers for advice surrounding health care decision making. Oftentimes they referenced physicians and social workers with programs such as PACE, where they received the bulk of their information on EOL planning. From these data and through personal interactions, there is evidence to support that caregivers were protective of their older adult loved ones with dementia. As anticipated, they were involved in decision-making processes that occurred as a family and with use of internal and external resources such as faith/spirituality or PACE health care personnel.

Discussion

The current study is the first to examine the understanding of EOL terminology among African American family caregivers of older adults with dementia. Most prior research examining the issue of EOL in African American older adults is focused on racial comparisons. Among African American individuals, social variables may differ and can contribute to within-group differences (Whitfield, Allaire, Belue, & Edwards, 2008). Thus, further research using a different approach was warranted. As seen in this study, understanding and meaning of EOL terminology differed among caregivers. Understanding of health care terminology is important as it relates to EOL planning, particularly among Black individuals (Moss & Williams, 2014). Family caregivers' understanding of EOL terms may differ from health care provider expectations, particularly when cultures differ (Moss & Williams, 2014). This disconnect may lead to misunderstanding or inaccurate interpretations, negatively affecting EOL experiences.

African American caregivers demonstrated that they were engaged in EOL decision making for their loved ones with dementia. In concordance with the health care literature, EOL decisions made by caregivers were not autonomous (i.e., independent acts) but instead family-centered and involved communication with health care providers as a resource. These findings are consistent with those of other recently published literature (Sanders, Robinson, & Block, 2016; Smith-Howell, Hickman, Meghani, Perkins, & Rawl, 2016), and serve as a reminder for health care providers to focus on the specific needs of the individual and family when using EOL terminology. Moreover, heavy reliance is placed on health care providers' (mainly nurses and physicians) input regarding EOL decision making, emphasizing the need

for health care providers to be sensitive to the needs of individuals and families within cultural contexts.

Death remains a deeply personal experience (IOM, 2015), as well as a familial and communal experience. The growing cultural diversity, inclusive of larger numbers of African American older adults in the United States, was part of the contextual variables in the development of the 2015 IOM report, "Dying in America." The findings emphasize that terminology matters when discussing EOL issues (IOM, 2015).

There are often inconsistencies in health care providers' expectations regarding understanding of EOL terminology and patients and families. Health care providers must be open to educating patients and families on this subject, and patients and families should be receptive to this education. Health care providers should also be open to being educated by their patients and families, as they are the experts on the reality of their experiences.

Patient and caregiver understanding of EOL terminology should be recognized by health care providers and honored when possible. In instances where issues exist between inconsistencies in care provision or communication, health care providers must recognize that this may be a difference in understanding. Health care providers also must be prepared to ensure that patients and families are thoroughly educated on what they are referencing when terms such as "end of life" are used in the health care setting/context. In the current study, interpretations of terms varied, and less miscommunications and/or unwanted interventions may occur when health care providers and patients/families understand each other. This finding provides evidence that culture-based care is essential to improving well-being, even in death (Leininger, 2002). Therefore, there is a need to focus on ensuring the needs of groups, such as African American individuals, are adequately addressed to provide optimal health care to all patients and families. As the largest health profession, nurses have opportunities through transcultural nursing to lead other direct care providers (i.e., discharge planners, case workers, social workers, chaplains, and physicians) by example, formal education, and interdisciplinary research. Care provided to patients and families must be offered without bias. Nurses, physicians, and all other members of the health care team must be culturally aware and sensitive to the needs of patients and families during care delivery regardless of care recipients' or providers' cultural backgrounds.

Limitations

The current study has limitations. Data were collected across several geographic communities, resulting in little time to establish relationships, as suggested by Corbie-Smith et al. (2007). However, careful consideration was taken to be courteous and respectful of all participants. Some socially desirable responses may have been provided during the interviews, but the fact that the interviewer was of the same race most likely put caregivers at ease. The same interviewer conducted all interviews, and steps were taken to avoid verbal and non-verbal indications of approval or disapproval of responses provided.

Conclusion

The current descriptive study using a qualitative approach contributes to the growing body of literature on EOL in African American individuals. Evidence of differences in understanding

of EOL terminology was demonstrated through interviews. EOL decision making is a process that involves family members and multiple resources, such as health care providers, reliance on faith or spirituality, and past experiences. These results also provide evidence that personalizing the approach used to address EOL care in the population of African American individuals with dementia is important. By gaining insight on the different uses of EOL terminology, African American caregivers can be helped in making EOL care choices for care recipients in a more informed, timely manner. It is also anticipated that by honoring the wishes of care recipients near the end of life in this population, other members of the family unit may be encouraged to make necessary plans for the end of their own lives. Lastly, the knowledge gained may assist researchers in developing and testing a culturally tailored intervention specific to the EOL needs of African American individuals with dementia. With clinical translation, this type of intervention will lead to the prevention of unwanted medical care near the end of life and more peaceful death experiences for patients and their families.

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