

U10A1 — Scientific Merit

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### **Introduction**

End-of-life care is often misunderstood. At the same time, end-of-life interdisciplinary teams often do not understand the cultural challenges within racial and ethnic communities. Practitioners in end-of-life care have a duty to resolve these misunderstandings. The NASW (2019) Code of Ethics Principle of Competence also dictates that social workers seek additional insight and consultation from community member experience when intersectional factors are involved. Through the adherence to these principles and with the goal of clarifying needs, Rhodes et al., (2017) enacted a research study that addressed ongoing concerns about limited knowledge of African-American community members in Texas and Utah at end-of-life.

The research study, “The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community,” is designed to gather direct participant knowledge and help alleviate the knowledge gap. The study adds in-depth, community-driven understanding of specific end-of-life support barriers within African American communities (Rhodes et al., 2017). The increase in understanding by practitioners in turn increases the chance of finding effective interventions and soothes the confusion of minority community members going through the process of end-of-life.

### **Study Description and Advances to the Field**

The qualitative study addresses the barriers to care and racial differences present within the African American community regarding end-of-life assistance and planning. A one year study by Rhodes et al. (2017) completed primarily in 2015 utilized both 90-minute focus groups and semistructured 18-question interviews to gather feedback from African American end-of-life patients, caregivers, or practitioners. The study authors partnered with university-affiliated

clinics in either Utah or Texas for permissions and participant inclusion. The authors interest was in sourcing both African-American caregivers and recipients of end-of-life care (or individuals who had experience in both capacities). Six participants completed the 25-64 minute interviews while eleven participants were engaged in the focus groups. Regarding the interviews, not only would participants be asked about their ACP knowledge, but they would be asked how to counsel other community members about the process of entering hospice or preparing an advance directive.

Purposive sampling within these settings was utilized, seeking racial specificity and connection to end-of-life, hospice, or palliative care experiences. This sampling interest provided an additive contribution to the research since previous studies typically sampled from one group or the other. Palliative care practitioners, ministers or caregivers were engaged along with patients on hospice services. Seventeen participants agreed to participate in the study which included community-based focus groups or interviews. The sampling offered complementary participant information for the basis of the study (Rhodes et al., 2017).

Thematic analysis was utilized to consolidate the recorded or transcribed information, after which a discussion was presented to help summarize the implications of the study and note limitations. The themes that were established were as follows: 1) Sharing personal experience with end-of-life care, 2) The importance of completing an advance directive, 3) Barriers to completion of ACP among African-Americans, 4) The benefits of palliative care, 5) The benefits to hospice, 6) The barriers to hospice enrollment, and 7) Strategies to overcome perceived barriers to hospice enrollment (Rhodes et al., 2017). These themes advance the knowledge of the

field for this population and help keep practitioners informed, competent, and better able to provide care (NASW, 2019).

By having participants who are practitioners in end-of-life care and end-of-life patients/families, knowledge was able to be synthesized to offer intervention suggestions that were previously lacking from the literature. This information both adds to the theories and advances the knowledge in the field. Though, as a side note, the research could be strengthened by expanding either the sample quantity (17 participants) or collecting additional interviews from community members of different cities (Capella University, 2019).

### **Contribution to Practitioner Awareness**

A narrative inquiry approach to the research allows direct feedback from community members who have experience with end-of-life to inform researchers of how best to meet the needs of community members (Leedy & Ormrod, 2019). First hand encounters are rich with personalized accounts of both positive and negative experiences that color understanding amongst researchers and practitioners. Being able to define what specific resistance points are helps both practitioners and community members advocate for an interventions solution that best fits the cultural, legal, and health needs of the community members. As social workers, removing stigmas and advancing adequate medical and civic options for vulnerable populations is an ethical responsibility as well as a professional competency requirement (NASW, 2019).

The study contributed additional understanding of African American resistance to and lack of awareness of Advanced Care Planning (ACP) along with implications for how to create a culturally-relevant intervention to increase ACP creation within this population (Rhodes et al., 2017). Being able to understand the rationale behind the disconnection between ACP and

African-American culture, helps inform practitioners of approaches that could fill the disconnection gap. With increased knowledge of ACP within African-American communities, end-of-life community members could increase their quality of life, lower their family members stress levels, and advocate for sound medical care for other community members (Rhodes, Teno & Welch, 2006). When positive experiences rather than negative experiences are able to influence community choices, communities feel more empowered as individuals and as a collective. Utilizing the resultant knowledge from the interviews also allows space for a different conversation between the practitioner / individual than what could have been the practitioners usual approach.

### **Scientific Method**

A research problem and research questions are posed so that increased understanding can emerge in the research (Leedy & Ormrod, 2019). The understanding assists with finding increased education, advocacy, and awareness amongst practitioners such that cultural competent support can be offered to diverse, and often outlier, community members. The article "The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community" examined the gap in the advance directive research within this population. Examining this gap provides scientific merit to the study as does advanced the knowledge in the subject area and providing good research (Capella University, 2019). This research problem of the study involves understanding perceptions within the African American community regarding ACP and utilizing hospice services while the two research questions below specifically address barriers within the community.

- 1) What causes resistance to advance care planning (ACP) or the utilizing of hospice services by the African American community?
- 2) What culturally-appropriate interventions can be used to promote awareness of ACP options?

Answering these two questions can help promote understanding by researchers and practitioners because they draw from direct community knowledge, practice, and values. The information gathered specifically from research participants creates cultural themes that express value-based understanding in order for practitioners to be increasingly sensitive to unmet needs of individuals within the African American community. Being able to understand the perspective of an individual who is fearful, uninformed, or inappropriate for these tools works in favor of providing culturally-appropriate interventions to assist communities in planning based on their values, needs, and wants. The themes identified in the interviews can additionally be explored in-depth and paired with interventions that could be additionally researched for effectiveness.

Good research conduct was provided in multiple ways. The semi-structured interviews gave detailed accounts of rationale and testimonials for thematic analysis while the focus groups offered 90-minute group analysis that was also transcribed and analyzed. Two coders analyzed and groups the data, with a third coder available for disputes. The participants were determined within a convenience sample from University-affiliated medical facilities and approved verbal consents as per UT Southwestern Medical Center Institutional Review Board policy (Rhodes, Elwood, Lee, Tiro, Halm & Skinner, 2017).

### **Credibility and Dependability**

According to Leedy and Ormrod (2019) approaches to qualitative research can have advantages over quantitative research based on six factors: exploration, multi-faceted description, verification, theory development, problem identification, and evaluation. The broad, yet focused questions in the interviews or focus groups fit the exploratory nature of the research study while the data collection procedure helped to identify and verify problems associated with the research question in order to create theories for culturally-appropriate interventions as solutions. The research problem in this study is identifying understanding of why African American communities are resistant to utilizing hospice care and making plans through an advance directive. The evaluation of participant input and well as comparative analysis of other research, helps draw credibility to both the need for the study and the results.

Rhodes et al. (2017) reported that less African American individuals than white individuals complete advance directives and the authors, as an ethical duty, are exploring rationales for the resistance. An exit survey study researching disparities between advance directive planning in individuals with deaths in 2001-2012 published that 74% of white deceased individuals had prepared an advance directive while only 38% of African American deceased individuals had one prepared at time of death (Koss & Baker, 2017). The main topic of this study is finding themes for barriers and benefits to receiving hospice care and creating advance directives among African American end-of-life-affiliated individuals.

Credibility is multi-faceted in that other people need to trust the methodologies used by researchers, find the data plausible, and agree with the appropriateness of the need for the research (Leedy & Ormrod, 2019). By comparing the resultant data that study researchers and past studies have engaged in creating, credibility can also be enhanced or reduced depending on

the parallel or divergence of the data. Koss and Baker (2017) shared knowledge of how increasing internet access has made it easier for Africa-American populations to be proactive about ACP when directed or educated about such options. When practitioners are given the ability to empower populations due to research results, dependability is also confirmed. An additional study by Collins, Zouha, Lockhart and Mixer (2018) relayed data concluding specific challenges in matching and educating cultural competent nurses to work with Africa-American populations. This cross-research comparison adds credibility and importance to sharing the resultant themes and intervention suggestions from the current research study across interdisciplinary care team members.

### **Ethical Considerations Analysis**

Ethical research was observed by attention to these three elements: Protection from harm, voluntary and informed participation, right to privacy. Having multiple options such as either a focus group or private interview helps reduce the risk of harm to the participant by letting them chose their option based on personal comfort. Voluntary and informed participation was observed in the study with the review of the IRB while the right to privacy was engaged by removing formal names from testimonials attached such that the gained information remains confidential (Leedy & Ormrod, 2019).

### **Conclusion**

Rhodes et al. (2017) described previous studies which place strong emphasis on lack of understanding along with misunderstanding cited amongst African American community members regarding ACP and hospice care knowledge. The research study specifically asked what the barriers within the communities were so that themes for understanding could emerge to

benefit increased education, advocacy, and awareness amongst practitioners regarding care to individuals within this community. The study conclusion reports community-based testimonials which increase understanding the perceptions within the African American community regarding ACP and utilizing hospice services. The use of narrative inquiry to make personalized and focus group semi-structured interviews draws directly from community experience in order to draw parallels of understanding from themes in the narrative analysis (Leedy & Ormrod, 2019).

This research keeps practitioners informed and competent in their field while better able to provide care. The testimonial analysis allows the practitioner understanding of how to open up a different conversation than the practitioner's usual approach. In understanding that there are misbeliefs from African-American individuals that hospice hastens death or goes against Gods-will, education and advocacy integration within intergenerational or church circles could assist with adding additional knowledge or insight to the conversations for those individuals that are curious or engaged in knowing more (Rhodes et al., 2017).

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