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A Cross-Cultural Qualitative Study: The Differences in Attitudes and Opinions on Advance Care
Planning Among African, Caucasian, and Latino Americans

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Abstract

The purpose of this study is to identify African American and Latino Americans' beliefs and attitudes about advance care planning (ACP) and compare these with beliefs held by Caucasian Americans. The objectives are to identify if there are differences in opinions between racial groups and to provide relevant information for health and social service providers. African American and Latino American participants in this study indicated many factors that affect their hesitation to utilize ACP services: spiritual and religious beliefs; family caregiving; and lack of knowledge about ACP services. Implications for practice include providing easy-to-understand information about ACP to clients of all racial and ethnic backgrounds.

Introduction

Advance care planning (ACP) involves learning about the different decisions that need to be made prior to an individual getting sick or dying; it includes discussing those preferences with other people. Topics that might be covered in ACP conversations include: ventilator use; living wills; do not resuscitate orders; power of attorneys; and hospice care. Research has indicated that racial minorities, including African Americans, Latinos, and Korean Americans, are utilizing ACP services—hospice care services in particular—less frequently than Caucasian Americans. It should be noted that Latino individuals may also identify as Caucasian or Black, and that Caucasians could also identify as African American, Latino, or Korean American. For the purpose of this study, these groups will be referred to by their racial differences. Caucasian Americans will refer to individuals who do not also identify as African American, Latino, or Korean American; the study participants who identify as African American, Latino, or Korean American do not also identify themselves as Caucasian.

Previous research has shown that racial and ethnic minorities indicate different factors that contribute to their underutilization of end-of-life services (Washington, Bickel-Swenson, and

Stephens 267). These factors, when present at the same time, create barriers that make it difficult for racial minorities to access correct and current information about the different aspects of ACP. With a growing population of older adults in the United States, and a growing proportion of racial/ethnic minorities, fewer Americans are planning for the end of life and fewer are utilizing advanced directives, living wills, and hospice care services. Factors such as language, religion, spirituality, and cost of healthcare are pushing minority populations to avoid seeking out end-of-life services (Born et. al. 247). It is imperative that we identify and eliminate the barriers to end-of-life care as the population of older Americans expands and grows in diversity.

The purpose of this qualitative study is to examine African Americans, Latinos, and Caucasian Americans of different ages to identify their beliefs and attitudes about advance care planning. The objectives are to identify whether or not there are differences in opinions about ACP between different racial groups, what factors influence racial/ethnic minorities' opinions about ACP, and to analyze these differences critically in order to identify the implications for social service providers. Furthermore, by identifying these belief systems and pinpointing different barriers to end-of-life services, service providers will be able to provide information and tailor care towards the client population defined as the racial/ethnic minority.

Literature Review

Research in the field of palliative care and diversity has largely centered on the barriers that racial/ethnic minorities—African Americans in particular—face in receiving end-of-life care, and these include what their attitudes and opinions are about these services. A common theme

that has been identified among African Americans is a mistrust of the healthcare system. Paul Rousseau found that feeling disenfranchised and mistrusting medical establishments influences African Americans to over-treat themselves as a result of not trusting doctors and certain doctor-recommended treatments (296). “Historical discrimination and racial inequalities ascribed to racial prejudice, mistreatment, and slavery,” [have] influenced African Americans to “cautiously err on the side of overtreatment rather than undertreatment” (Rousseau 296). Previous research reports that African Americans tend to exhibit a mistrust of the general health care system and believe that the system controls treatment, not patient wishes (Born et. al. 247; Perkins et. al. 48). In this area of research, mistrust “refers to the belief that health in the United States is driven by powerful economic and societal forces rather than the best interests of the patient” (Born et. al. 253). Not trusting the U.S. healthcare system can greatly damage an individual’s beliefs about receiving medical care, particularly in the later stages of one’s life because one can often have misconceptions about how different services are delivered and what those service options actually entail.

Despite a large mistrust of health care, African Americans often prefer to seek aggressive treatment at the end of life. Amber Barnato et. al. note that “blacks are more likely to die in a hospital...and [use] life-sustaining treatments such as mechanical ventilation (MV), hemodialysis, and feeding tubes” (695). It is hypothesized that African Americans seek extensive treatments at the end of life because they have spiritual beliefs that conflict with the goals of palliative care and they distrust the healthcare system (Johnson, Kuchibhatla, and Tulskey 1956). Although they may seek extensive treatment toward the end-of-life, African Americans have also expressed wishes “to die a peaceful death” if nothing more could be done for them (Torke et. al.

596). This wish is grounded in the belief that many life-prolonging treatments would no longer be worthwhile after a certain point; many participants would prefer to be let go. While African Americans might prefer to seek aggressive treatment initially, Latinos often prefer medical care focused on comfort rather than extending life. Older Latinos run into difficulty obtaining the care they prefer because they are less likely to express their wishes to family members or doctors; therefore, they often receive treatment inconsistent with their values and preferences (Kelley, Wenger, and Sarkisian 1109). In addition to not expressing their preferences and wishes, racial/ethnic minorities often are less likely than Caucasian Americans to complete advance directives or have a living will (Johnson, Kuchibhatla, and Tulskey 1956).

When making medical decisions, racial/ethnic minorities often prefer receiving care from family members as a first choice. Previous research notes that the role of family is an important factor that affects African Americans' and Latinos' decisions regarding hospice care and other end-of-life services (Dillon, Roscoe, and Jenkins 175; Torke et. al. 593). African American participants in this study indicated a strong preference to involve family in treatment decisions: "you need somebody there who knows how you like things to go and that's [going to] make sure it happens" (Dillon, Roscoe, and Jenkins 184). By involving family members, individuals felt as though their wishes would not only be known but articulated and followed. Marya Cohen et. al. also emphasize that family roles are most important to Latino families when making end-of-life decisions (1429). In particular, "consensus among family members" was of utmost importance because having large family networks created opportunities for conflict. Research in the field of palliative care has found that racial/ethnic minorities utilize end-of-life services less often than Caucasian Americans for many different reasons (Washington, Bickel-Swenson, and Stephens

267). It is imperative that these populations are given proper information regarding end-of-life services, such as hospice care, and that service providers begin to tailor care to align with the values and beliefs of African Americans and Latinos.

Methodology

This qualitative study was completed through interviews with African Americans, Caucasian Americans, and Latinos in Wood County, Ohio. The United States Census Bureau estimates the county's population to be: 93.5% "white alone;" 2.8% "Black or African American alone;" 5.3% "Hispanic or Latino alone;" and 1.8% "Asian alone" (United States Census Bureau, n.d., consulted 2016). It should be noted that the population of Korean Americans in Wood County, Ohio is not counted for in its own category; rather, it is included in the estimates of the "Asian alone" population. Open-ended interview questions allowed interviewees to express their thoughts, opinions, and beliefs fully about different topics related to advance care planning. A survey would have restricted the participant's responses by forcing them to answer from a set of chosen answers; such a format would not have allowed for any further explanation. Confidential interviews were completed with individuals acquainted with the researchers. Using the snowball method, after completing the initial interviews, researchers asked participants to connect the researchers with other family members and friends. All of the interviews were voice recorded, and then transcribed verbatim. The content was analyzed to identify common themes in the participants' responses. The interview responses were analyzed as a whole group, and also by race/ethnicity and age of the interviewee, in order to identify trends in response to themes.

Findings

By the end of the study, ten qualitative interviews had been conducted with five African Americans, three Latinos, and two Caucasian Americans. All of the participants were female, ranging in age from twenty to eighty-five years old. The findings from these interviews uncovered several common themes surrounding ACP for African Americans and Latinos including the role of family in end-of-life decisions, the level of understanding about ACP services, and the impact of religion and/or spirituality.

Role of the Family

All three racial/ethnic groups identified the importance of family in planning for and attending to the end of one's life. For African Americans, three out of five participants stated that they would like their family to be involved when making decisions about the end of life. In addition, four of the African American interviewees identified family members as their primary source for information about hospice and end-of-life services. All five of the Latino and Caucasian American individuals who participated in this study also identified a desire to include family in conversations about ACP and other end-of-life services. One participant, a sixty-four year-old Latina woman, stated, "I've been around [my family] for a long time and I think they know what I would want done." One of the Caucasian American participants, a twenty-two year-old female, said, "my family and loved ones are in a position that they could care for me at home, so I would probably prefer that at this juncture in my life." Another participant, a twenty year-old Latina female, identified the need for hospice services "when [an individual] cannot help themselves and can't get help from family members."

Many of the interviewees in this study stated a preference to be cared for at home and by family members before ever turning to long-term care centers or hospitals. When asked where she would prefer to pass away, one twenty-eight year-old Caucasian female said, "I would prefer to be at home." Eight of the ten interviewees showed a preference to spend their last days at home surrounded by family members and friends. These findings indicate very little difference between the racial/ethnic groups surveyed as it relates the importance and involvement of family at the end of one's life.

Level of Understanding about Advance Care Planning

Another factor that seemed to play a role in participants' opinion about advance care planning is the level of understanding about related services. The Caucasian American and Latino participants exhibited a detailed understanding about ACP, hospice services, and insurance coverage for end-of-life services. All five of these participants identified the meaning of a living will, a health care power of attorney, and a do-not-resuscitate order; they also showed that they understood insurance coverage in relation to hospice services. On the other hand, four of the five African American interviewees demonstrated very little to no understanding about advance care planning. One interviewee, a seventy-six year-old African American female, stated, "I have heard about healthcare planning but I do not really understand," whereas a twenty-one year-old African American female stated, "I know a little bit."

Impact of Religion & Spirituality

Religious and spiritual beliefs have an impact on an individual's expectations about how one would like the end of life to play out. Seven out of the ten participants identified religion as having a large impact on their decisions about end-of-life care. A twenty-two year-old Caucasian female stated, "my belief that there is something beyond this world kind of affects my comfort level with making certain decisions." Interviewees who spoke about their belief in something happening after death were likely to express a preference for "letting go" if there was nothing more that could be done for them. One participant, a twenty-eight year-old Caucasian female, said, "my belief in what happens after death...impacts my decision of I don't need to hang on here any longer if I'm at that point." Similarly, a sixty-four year-old Latina female, expressed, "if I'm really old and I know there is nothing else to be done, I would probably call the church and have someone there." Interestingly, one participant's lack of religious beliefs pushed her to consider hospice services more strongly; "I don't know what comes after death, so I would like to at least be in as little pain as possible. While religious and spiritual beliefs, or lack thereof, affect Latino and Caucasian Americans' decisions about end-of-life care, a majority of the African American participants answered that their religious beliefs would not play a role in their use of end-of-life care.

Discussion

After analyzing the findings from all ten interviews, one can conclude that the African-American participants' opinions and knowledge about advance care planning differ from the attitudes of Caucasian Americans and Latinos. Previous literature identified strong religious beliefs as having more of an effect on racial/ethnic minorities' decisions about end-of-life care

(Born et. al. 251), but this study found that African Americans' end-of-life decisions were less likely to be impacted by religion than those made by Caucasian Americans and Latinos. Very few of the African American participants indicated religion or spirituality as an important factor in end-of-life planning, whereas all of the Latino and Caucasian American participants discussed its importance in ACP. The results from this study also show that African Americans are less likely than Caucasians and Latinos to demonstrate that they understand what is meant by hospice services, ACP, and other related topics. It is difficult to use end-of-life services if one does not know about them or understand their purpose. Service providers—whether they be doctors, social workers, or religious figures—need to be sure clients are receiving proper information about ACP before end-of-life care becomes a concern; the earlier these conversations happen, the more prepared clients and their families will be when the end of life nears.

It is important to note that Latinos were more likely to have similar beliefs to Caucasian Americans rather than to African Americans as previous research has suggested. However, one concept that was mentioned across all racial/ethnic and age groups is the preference to be cared for at home by family and friends before considering end-of-life services. In addition to comparing the responses of different racial/ethnic groups, the results were also analyzed by age group. It was found that younger individuals were more like to have a better grasp of advance care planning than older adults. This phenomenon could be due to the rise in popularity and use of hospice and other end-of-life services in the past few decades. It may also be possible that older adults are not being given adequate information about ACP services, and instead are being left to learn what little they can from family members. One participant stated that she learned about ACP services from “a family member, and a lot of [her] students have gone into the field

of geriatrics and work with hospice care.” In addition, three of the five African American interviewees indicated that they received information about hospice care from family members, and not from a doctor or other medical professional. The findings from this study may suggest that Latinos and African Americans do not have as much in common in reference to end-of-life care as may have been previously emphasized in other similar studies.

It is very difficult to generalize the results from this study because of many different research limitations. The participants in this study are not representative of the greater population and the sample size is fairly small. The group of ten interviewees consisted only of female subjects, all of whom identify as at least middle class. Not only did this study lack variation in gender and socioeconomic status, all of the participants reside in rural Northwest Ohio. The demographics of this sample fail to account for the opinions of males, individuals of different economic status, and people in different geographic regions. By constructing a sample that is more diverse and larger in size, it may be easier to identify findings that can be applied and generalized to a larger group of the population.

Future research studies in this field should aim to gather data from a large group of individuals from a variety of different backgrounds. It is recommended that individuals of Native American, Asian American, and Native Hawaiian and other Pacific Islander background be interviewed. By focusing research on specific racial and ethnic groups, future researchers might be able to identify better the exact differences between the groups. Identifying these differences will help service providers better understand how clients of different backgrounds might approach the topic of ACP and end-of-life services. It is also recommended that future research include

responses from providers of end-of-life services. Including the providers of these services might offer a better understanding of what kind of information is given to clients in need of ACP services. This method will also help create a more complete picture about the delivery and utilization of advance care planning because providers can attest to the type of clients for whom they typically provide services. It would be extremely beneficial to continue to utilize qualitative research methods when completing research in this field of study. Having the opportunity to gather unrestricted, unfiltered responses from participants—and potentially service providers—would allow researchers to gather as much information as possible.

These findings indicate that it is important for social service and health care providers to be cognizant of the way they deliver information about ACP services, including hospice care, to clients. It is imperative that information be delivered in a manner that individuals of all demographic backgrounds can understand, as half of the participants in this study mentioned that they did not understand end-of-life services. Not having correct information or being provided confusing information about ACP services can make it difficult for individuals to have conversations that prepare them for end-of-life decisions. All of the participants who stated not having spoken to a loved one or medical professional about end-of-life planning also reported having little to no understanding about those services. If individuals were properly educated and aware of the services available, they would be more likely to utilize them, or at least have conversations about the resources available to them.

When service providers speak with clients about end-of-life care options, it is important to be aware of the clients' religious beliefs. Many of the participants in this study indicated that their

religion or spirituality played a key role in the decisions they would make at the end of their life. One participant, a twenty-eight year-old Caucasian American female, stated, “I think my belief is what happens after death...impacts my decision of I don’t need to hang on here any longer.”

Another participant, a twenty year-old Hispanic American female, said that she would like to be in as little pain as possible as she nears the end of life because “[she] doesn’t know what comes after death.” Social service and health care providers need to be sure they are not discrediting or ignoring a client’s religion; these beliefs should be integrated into the information and options provided to clients about the end of life, and will also help provide services that align with clients’ beliefs.

It is also important for providers to be an objective party in ACP discussions. If service providers allow their personal values and beliefs to affect their work, then that individual might persuade clients to choose, or not to choose, certain end-of-life care options. By integrating all of these implications into social service provision, clients from all demographic backgrounds will better be able to access and use ACP services. The goal is to provide comprehensible information about ACP to the community and its citizens, as well as engage clients in conversations about end of life that are cognizant of one’s values, religious or spiritual beliefs, and understanding about ACP services.

Conclusion

The findings from this study provide some insight as to why individuals, not just racial/ethnic minorities, are underutilizing hospice care and other end-of-life services. While this study does not have an explicit international focus, the conclusions drawn from the research can be directly

adapted to an international context. End-of-life is a universal experience, but each culture approaches the life stage with unique traditions, beliefs, and expectations. It is important that each culture have access to information that is relatable and accessible to its population. These findings can assist social service and health care providers in reconsidering how their organizations are delivering important end-of-life information. Being able to adapt agency policy and personal practice to a diverse client population can ensure that providers are making information accessible to an increasingly racially/ethnically diverse world. Information about end-of-life care should be delivered in a manner that takes into account a client's demographic background, understanding of ACP, religious/spiritual beliefs, and the importance of including family in the decision-making process.

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