Published in final edited form as:

Am J Hosp Palliat Care. 2021 June ; 38(6): 618–625. doi:10.1177/1049909120988280.

Spirituality and the Illness Experience: Perspectives of African American Older Adults

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Abstract

Background: Disparities in hospice and palliative care (PC) for African Americans have been linked to mistrust toward the healthcare system, racial inequalities, and cultural preferences. Spirituality has been identified as important to African Americans in general. Less is known about the influence of spirituality on African American illness experiences.

Objective: The goal of this study was to understand older African Americans' perspectives on how spirituality influences chronic illness experiences to inform the development of a culturally tailored PC intervention.

Methods: In partnership with 5 churches in the Denver metropolitan area, we conducted focus groups with African American older adults (n = 50) with chronic health conditions and their family caregivers. Transcripts were analyzed using a deductive approach. The theoretical framework for this study draws on psychology of religion research.

Results: Themes referenced participants' spiritual orienting systems, spiritual coping strategies, and spiritual coping styles. Psycho-spiritual struggles, social struggles, and sources of social support were also identified. Findings suggest African Americans' spirituality influences chronic illness experiences. Participants relied on their spirituality and church community to help them cope with illness. In addition, social struggles impacted the illness experience. Social struggles included mistrust toward the healthcare system and not being connected to adequate resources. Participants expressed a need to advocate for themselves and family members to receive better healthcare. Churches were referred to as a trusted space for health resources, as well as spiritual and social support.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Keywords

health care disparaties; qualitative research; African American; older adults; spirituality; palliative care; community engagement; faith-based

Background

Palliative care (PC) improves outcomes for seriously ill individuals by improving quality of life, decreasing symptoms, and ensuring health care is consistent with patient and family caregiver goals and preferences.[1,2] Despite the benefits of PC, African Americans are less likely to receive hospice or PC, less likely to have pain effectively managed, and have lower rates of advance care planning compared to whites.[3–11] These well-known disparities have been linked to many underlying factors, including racial inequalities, mistrust toward the healthcare system, and cultural preferences.[5–7] The National Consensus of Hospice and Palliative Care Guidelines[12] emphasizes the need for healthcare professionals to support patients' spiritual values and address disparities in PC.

The importance of spirituality in the lives of most African Americans cannot be overstated. Studies suggest spirituality is linked to patient outcomes, including quality of life, anxiety, and depression.[13,14] A recent review of African American perspectives on spirituality notes that "the religious culture of this population has historically embraced and transmitted a set of beliefs and practices that have extended to the church."[15 (p339)] African Americans are likely to report a formal religious affiliation (e.g., 87% in 1 study).[10,11] Religion is defined as an expression of spirituality in which people share values, beliefs and meanings (e.g., the Church of Latter-day Saints, Hindus, United Methodist).[16] In the current study, the church is referred to as a religious faith-based community. Regardless of religious affiliation or involvement in religious institutions, African Americans are encouraged to rely on their religious beliefs and spiritual practices to cope with life's stressors.[15]

The church can be a resource for improving health disparities in African American communities and positively influence health perspectives and behaviors.[17–22] Churches are respected and trusted, making them safe spaces to engage in PC conversations.[18,20] There have been a few initiatives to improve the use of PC and hospice for African Americans through faith-based communities.[18,20,22] However, little research has focused on the perceived impact of spirituality on African American illness experiences.

To inform the development of a culturally tailored and wholistic PC intervention, we developed an innovative partnership with local churches and a community-based organization. We conducted focus groups at 5 churches with African American older adults living with chronic health conditions. Focus groups explored the impact of spirituality, the church, and other social support on illness experiences.

Theoretical Framework

The theoretical framework for this study draws on psychology of religion research, particularly research on spiritual coping (or *religious coping* when focused on religious practices).[16,23–26] People often turn to spirituality as they cope with serious and chronic

health conditions.[27–30] Spirituality helps people understand their illness experiences, make value-based healthcare decisions, and engage in practices that promote well-being while living with chronic illness.[16] Illness can compromise well-being by prompting or exacerbating psychological distress (e.g., anxiety, depression, hopelessness, anger)[30] and/or spiritual distress (e.g., abandonment by God, questions of meaning).[31–33] People rely on spirituality to help cope with illness using 4 general styles: self-directing, deferring, collaborative, and surrender.[24,34] Even if people have a strong relationship with God (or what is sacred to them), they may use a *self-directing* style where they rely on themselves to cope.[34] People who use a *deferring* style rely on God to cope.[34] With a collaborative approach, people partner with the divine.[34] When using a *surrender* style, people acquiesce to God's will to cope with illness, even if it is not their first choice.[35]

Methods

In September and October 2019, we conducted focus group interviews with church members who identified as African Americans living with at least one chronic health condition and their family caregivers. The Colorado Multi-Institutional Review Board approved this study.

Recruitment

We developed an innovative partnership with 5 Denver metropolitan area churches and the Colorado Black Health Collaborative (CBHC),[36] a community-based organization that works to improve health and wellness in African American communities. CBHC contacted leaders associated with health ministries by email, describing the study, and inviting recipients to contact the researcher. Five health ministry representatives responded from 5 predominately African American churches (Catholic, Baptist, and Methodist). After further dialogue with representatives and their pastors on the objectives of this study, we conducted one focus group at each church. Pastors approved the project but were excluded from the focus groups because of their potential influence on the participants.

Health ministry representatives helped identify and recruit focus group participants. Recruitment flyers were placed in church bulletins and verbal announcements were given at each church. We targeted African American church members over the age of 55 with one or more chronic illnesses. Family members who care for someone with a chronic illness were also invited to participate.

Focus Group Protocols

The interview guide was developed by members of the University research team (S.S. and S.F.) and a health ministry's representative who also served as the focus group co-facilitator. Topics and questions were informed by the literature review and the research team's experiences with PC and community-based research. We used open-ended questions such as: In what ways have your spiritual beliefs helped you? Can you give me an example of a time that your spiritual beliefs influenced a decision about your healthcare treatment? In what ways have you used your church to support you in your journey? If you or a loved one became progressively ill and you needed health information, social service information, or family help, who would you talk to? See Table 1 for focus group question guide. At the end

of each focus group, we administered a nine-question survey on social demographics and PC knowledge (Table 2).

We conducted one focus group at each of the 5 churches. Each group lasted approximately 90 minutes. The PI (S.S.) facilitated all focus groups with a co-facilitator and a note-taker, both selected by CBHC. The note-taker observed and recorded group dynamics and themes discussed. All groups were audio-recorded and transcribed for analysis. All respondents gave verbal consent to participate. Focus group participants received a $30.00 gift card to compensate them for their time.

Analysis

Two researchers (S.S. and K.A.) independently analyzed focus group transcripts using a deductive content analysis approach.[37] Data were discussed and major coding themes (domains) and subthemes (components of each domain) were developed using psychology of religion literature.[16,23–36] Both explicit and implicit references to aspects of participants' spiritual orienting systems, spiritual coping strategies, and spiritual coping styles were identified. We also identified psychospiritual struggles, social struggles, and sources of social support.

Themes and subthemes were defined and refined through a series of meetings. Member checking was conducted with church representatives who were present in the focus groups and was discussed in a collaborative 90-minute meeting. This feedback helped the research team revise and validate themes and patterns within each domain. The primary feedback given was on the themes of psycho-spiritual and social struggles. Exemplar quotes were selected to represent each theme and subtheme. A demographic and PC knowledge survey was analyzed using simple descriptive statistics.

Results

Participants' Demographic Characteristics

Fifty participants were recruited to participate in focus groups. Within these groups, 6 people identified as family caregivers. Each focus group had a health ministry representative attending as a participant or observer. Participants ranged in age from 55 to over 90 with 76% of participants being 65-84 years of age. The majority (84%) were female. Religious affiliations included Baptist (60%), Methodist (22%), and Catholic (18%). All participants claimed one or more chronic health conditions, of which hypertension (64%), diabetes (30%), and heart failure (20%) were most prevalent. Only 10% of participants were hospitalized in the past 3 months, 60% had not heard the term PC separate from hospice care, and 90% would welcome PC education in a church-based setting (Table 2).

Themes

Focus group transcripts yielded 5 themes related to the impact of spirituality and the church on the illness experience: (1) *spiritual orienting system,* the influence of *spiritual values, beliefs, and meanings* on health and healthcare decision-making; (2) *psycho-spiritual struggles* associated with the illness experience; (3) *social struggles;* (4) *spiritual coping*

with illness experiences; and (5) *social support and resources.* Table 3 provides an overview of themes and subthemes.

Spiritual Orienting System

One's spiritual orienting system (SOS) includes *spiritual values, beliefs, meaning,* and *practices*. SOSs help people create and maintain a coherent understanding of the world and their life experiences. Values/beliefs discussed were related to having faith and hope: faith that God exists, and faith that God protects and provides. In making meaning about life and illness, one participant explained that he has "a strong, strong belief that [God's] keeping him here for a purpose." One participant reflected on a Bible given to him by his mother when he was a child. It reminded him of his spirituality and helped him cope with chronic illness. He went on to say, "my mom told me this, you know what we taught you, we accepted Christ at a young age." Spiritual values and beliefs can be reinforced by illness, as exemplified by one participant, "I have been tested and it made my belief even stronger because I have a lot of medical problems."

Practices such as personal prayer, reading the Bible, showing gratitude, and giving to others were mentioned. Participants indicated that focusing on gratitude and giving to others through the church community were distractions from illness: "We're not dwelling on our illness, our disability, because we're helping somebody else."

The importance of sharing a value for spirituality with healthcare providers was brought up. One person revealed, "I ask my doctors, do you believe in God? Are you spiritual? … That's the first thing I ask... I want to know we are on the same page." Another described her experience:

"When I was going through my cancer treatment, I went through 12 different doctors and about four or five different cancer centers until I found one with a doctor that connected to my spirit and when connected with my spirit, I knew then I was gonna be taken care of… I was gonna be okay."

Psycho-Spiritual Struggles

Psycho-spiritual struggles refer to emotional and spiritual distress that threatens a person's SOS and/or their sense of wellbeing. [16] Participants discussed the concerns they had related to faith, healing, and the future. A family caregiver mentioned struggle as her mother faced the end of life: "I'm wondering where is God in this? I know He's there with my mother because her spirituality is there … Between my faith and the fact that I got to go through this, I know sooner or later I'm gonna have to face it."

Social Struggles

The social struggles encountered by older African Americans were discussed and further confirmed with health ministry representatives. These included experiences of racial inequality, mistrust toward healthcare professionals, and challenges accessing adequate resources. This theme was directly derived from participants' responses and interwoven within other thematic categories. Participants said one reason spirituality is so important to

African Americans is that this population has relied on spirituality to cope with systemic racism for generations, as expressed by this participant, “I think people of color, we had no choice but to have a source, we had to have a source because the way we were treated as people, not equal, you had to have a relationship with God.”

Participants expressed feeling disregarded in healthcare settings. Family caregivers, in particular, noted the frequent need to advocate for better care for family members. Participants depended on family, friends, and church members to help them navigate the healthcare system to receive the best care. Many people felt as though they were being marginalized and therefore not connected to the proper resources as exemplified in this quote: “There’s a double standard in our society today. People of color are not exposed to resources like other cultures.” Another participant stated:

We as, you know, black people, they think we dumb, stupid, and black and you know… I don’t know what they know.… I’m not a doc, but we’re going to have to start asking some of those dumb questions we think.

Participants mentioned the need for financial assistance, referrals to doctors, medication information, and helpful questions to ask their healthcare team.

Spiritual Coping

Spiritual coping is relying on spiritual values, beliefs, meanings, and practices to cope with stress, heal, and restore well-being.[24,25] Participants noted that relying on their spirituality and church community helped them cope with their illness. Comments illustrate all 4 styles of spiritual coping: *deferring* (relying on God/the sacred), *self-directing* (relying on self), *collaborative* (working with God), and *surrender* (following God’s will).[24,34] The least common styles were self-directing and deferring. The most common coping style was collaborative, and some participants considered God to be a member of their healthcare team. In general, spirituality was viewed as a positive dimension of the illness experience as reflected in the following quote: “The spiritual part has a lot to do with my healing process.”

Social Support and Resources

Social support is the perception and actuality that one is cared for, can rely on other people, and is part of a supportive social network.[38] Participants expressed an intense interest in being connected to trusted resources. The church was considered a trusted source for health information. Many participants relied on health ministry leaders or friends in their congregation for resources and education. While some felt comfortable coming to their pastors regarding their health needs, others were reluctant. Some people thought their pastor was busy or said they were private people who didn’t want to share with their pastor. Having an advocate to connect them to resources was mentioned across all focus groups. While some relied on their family, friends, and church to be this advocate, others mentioned the need for an advocate. When asked who a good advocate would be, one participant said, “I think someone in the church would be really helpful because sometimes I guess it seems like they’d be more trustworthy.”

Discussion

This is one of the first studies to examine the impact of spirituality, the church, and other social support on the illness experience for African Americans. Examining participants' responses through a psycho-spiritual framework provides a foundation for understanding the influence of spirituality and the church on chronic illness experiences. Helping people draw on spiritual resources can enhance health outcomes among African American caregivers who need support.[39,40]

Implications for Practice

Findings on the impact of African Americans' spiritual values, beliefs, meanings, and practices on health and healthcare decision-making are consistent with existing literature.[15,39–42] The themes we found emphasized the importance of the healthcare team valuing patients' spirituality. Even as this value is acknowledged, studies reveal that healthcare providers lack the confidence and education to provide spiritual support.[43,44] Further, healthcare providers may feel that patients' and families' spiritual beliefs conflict with the provider's understanding of hospice and PC (e.g., "leaving it in God's hands" or "God will take care of me").[8,10] While some participants in this study exemplified a surrender coping style (following God's will), the majority of participants in this study used a collaborative coping style ("God is a member of my healthcare team"). Studies show that a *collaborative* coping style yields the most positive outcomes.[34,45,46]

Mistrust toward the healthcare system was a social struggle consistently discussed throughout each focus group and is commonly highlighted in the literature.[3–5,18,47] In previous studies, mistrust has been linked to past injustices toward African Americans and ongoing disparities within the healthcare system.[3,47] Mistrust may impact healthcare decision making.[47,48] PC providers can build trust by eliciting patient/family values, providing information about care options, respecting preferences, expressing empathy, and engaging in shared decision making.[47] It is also essential for providers to address spiritual needs by asking patients about the role of spirituality in their illness experience,[47,49] and being open to faith community involvement in care.[47] Involving faith communities may help lessen misunderstandings and longstanding mistrust.[18] Studies suggest the church is viewed by many African Americans as a trusted source of social support and health resources.[20] Partnering with faith-based institutions to provide healthcare education and develop trusting relationships may result in greater trust in the healthcare system and greater use of PC services.[18]

While the goal of this study was to examine perspectives on spirituality and the church on chronic illness experiences, focus group results may also serve as a foundation for a faith-based intervention that includes attention to spirituality and the ways it is used to cope with illness. Also, several PC studies have demonstrated that a peer navigator from the community can serve as an advocate for patients and family caregivers and help facilitate goals of care.[50–53] Training health ministry individuals or other church leaders to be navigators may increase education about and overcome barriers to PC by establishing trusting relationships with patients and their families.[52,53]

Limitations

Some limitations should be considered. We invited family caregivers but only 6 caregivers participated in this study. The 5 churches in the study are within 20 miles of each other in the Denver metropolitan area. The 5 churches only represent some Christian perspectives and are not spiritually diverse. Health ministry representatives participated in the focus groups. This type of focus group study may not be easily replicated in other church communities that lack support or health ministry leadership.

Conclusion

Participants illuminated the impact of spirituality and the church on chronic illness experiences. Further study is necessary to understand the impact of spirituality and the church on older African Americans of non-Christian beliefs and with various illnesses. There is a need to use these findings to develop and implement culturally-tailored interventions that include partnerships among healthcare, community, and faith-based organizations. Our findings support the need for PC interventions with African Americans living with chronic illness to include spirituality and explicitly address current and past experiences of racism and other struggles with the healthcare system.

Acknowledgments

The authors would like to thank Colorado Black Health Collaborative and church health leaders for their recruitment and collaboration throughout the research process.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Institute on Aging Multidisciplinary Research Training in Palliative Care (5T32AG044296-05).

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Table 1.

Focus Group Question Guide

Spiritual and Social Support a. Many people feel that spirituality is important, and that there is a connection between spiritual beliefs and a sense of well-being: **In what ways have your spiritual beliefs helped you?** b. Can you give me an example of a time that your spiritual beliefs influenced a decision about your healthcare treatment? c. Some people find it helpful to confide in their church community: In what ways have you used your church to support you in your journey?
Probes: 1. How comfortable are you with sharing your healthcare concerns with someone at church? 2. Please give an example of a time you informed someone in your church about your health? (tell a story).
Resources a. **We are interested in your resources and support:** If you or a loved one became progressively ill and you needed health information, social service information, or family help, who would you talk to? -What resources would you use? b. **What are ways the healthcare team could work with the church community? Probe:** For example, a church leader or health minister being a resource to connect someone with a healthcare referral. A church leader praying with the healthcare team or being there during difficult decisions about treatment.
Probe: 1. What are you experiences with your healthcare team and church community *working together* to address your health needs?

Table 2.

Social Demographics and Palliative Care Knowledge Survey

Question	Response (N=50)	n (%)
Church denomination	Baptist	30 (60)
	Catholic	9 (18)
	Methodist	11 (22)
Age	55-64	6 (12)
	65-74	16 (32)
	75-84	22 (44)
	≥ 85	6 (12)
Gender	Female	42 (84)
	Male	8 (16)
Chronic health conditions	Cancer	6 (12)
	Diabetes	15 (30)
	Heart Disease	10 (20)
	Kidney Disease	6 (12)
	Pulmonary Disease	9 (18)
	Hypertension	32 (64)
	Other	10 (20)
Hospitalized in the past 3 months		5 (10)
Heard of "palliative care" separate from hospice care		20 (40)
Would like information about palliative care through the church		45 (90)

*Six participants identified as caregivers

Table 3.

Themes, Concepts, Subthemes, and Text Exemplars

Themes	Concept	Subthemes/Text Exemplar
Spiritual Orienting System (SOS)	Values, beliefs, meanings, and practices of ultimate importance that help people make decisions and create a coherent understanding of the world and their experiences. [25]	Values: “So I try to thank [God] for waking me up every day and allowing me to do, or try to do, the right things each day, and it’s paramount. It’s just something that I was brought up and raised.” Beliefs: “I was certain the Lord was taking care of me.” Meanings: “I have a strong, strong belief that [God’s] keeping me here for a purpose.” “A lot of our stuff that we go through is genetics. We inherit a lot of things that we go through as far as health wise.” Practices: “If you do not pray, do not study your word, 9 times out of 10 you're not going to be successful with a healing process.” Shared SOS with Healthcare Providers: “I asked my doctors: ‘Do you believe in God? Are you spiritual?’ That’s the first thing I ask because I want to know the one who's administering to me, are we on the same page.”
Psycho-Spiritual Struggles	Emotional and spiritual distress that threatens a person’s spiritual orienting system and/or their sense of well-being.[16]	“You know, this [health condition] is a heavy burden, and I don’t know if I can deal with this.” “The last time that I had to go to the hospital, I couldn’t walk, and I’d pray each day. And when I woke up that morning I prayed to God. Like I was saying, ‘Am I going to walk? Am I going to walk?’”
Social Struggles	Experiences of racial inequality, mistrust toward healthcare professionals, and challenges accessing adequate resources.	“I think we need to start using these resources because you know they're there and somebody is using them, I'm sure. But if we don’t know, we can’t use what we don’t know.” “There's a double standard in our society today. People of color are not exposed to resources like other cultures”
Social Support and Resources	The perception and actuality that one is cared for, can rely on other people, and is part of a supportive social network.[38]	“I love my church…when you have a group that is praying for you and praying with you, that helps. It helps me as a caregiver and I'm hoping it kind of helps my husband as well. You know, he doesn’t go to church, but still it helps me.” “We [the church] provide them with resources because there are some community services that if they don’t have to go more than a 10 mile radius, we will pick them up and take them.” “What we’ve come to understand and do as a family, is when one of us is in the hospital, we have patient advocates within the family who are there.”
Spiritual Coping	Relying on spiritual values, beliefs, meanings, and practices to cope with stress, heal, and restore well-being. [16,24]	Deferring Style (rely on God/the sacred): “Okay, God, I'm trusting in you. I give my life to you and that I'm just gonna have to trust. In order to get through this, I'm going to have to just put my full trust in you and be okay with whatever the situation is.” Self-directing Style (rely on self): “You know, I didn’t use my spirituality to make a decision after I had all the surgery and stuff like that. I just went on my own and started doing some, some research.” Collaborative Style (partner with God): “I consider the Lord a member of my health team.” Surrender Style (do what you can and surrender to God’s will): “I don’t worry about it anymore or concern myself with it and all my prayers for the most part always end with ‘your will be done.”

Am J Hosp Palliat Care. Author manuscript; available in PMC 2021 June 01.