

Original Article

Cite this article: Hamilton JB, Best NC, Wells JS, Worthy VC (2018). Making sense of loss through spirituality: Perspectives of African American family members who have experienced the death of a close family member to cancer. *Palliative and Supportive Care* **16**, 662–668. <https://doi.org/10.1017/S1478951517000955>

Received: 18 April 2017

Accepted: 4 October 2017

Key words:

Palliative care; End of life care; Bereavement; Spirituality; Cancer; African American family members

Author for correspondence:

Jill B. Hamilton, Nell Hodgson Woodruff School of Nursing, Emory University, 1520 Clifton Rd NE, Atlanta, GA 30322. E-mail jbhamil@emory.edu

Making sense of loss through spirituality: Perspectives of African American family members who have experienced the death of a close family member to cancer

Jill B. Hamilton, PH.D.¹, Nakia C. Best, M.S.N.², Jessica S. Wells, PH.D.¹ and Valarie C. Worthy, M.S.N.³

¹Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia; ²School of Nursing, University of North Carolina at Chapel Hill, North Carolina and ³Sisters Network, Inc., Triangle Chapter, Durham, North Carolina

Abstract

Objective. Among African Americans, spirituality is meaning or purpose in life and a faith in God who is in control of health and there to provide support and guidance in illness situations. Using qualitative methods, we explored the use of spirituality to make sense of the end-of-life and bereavement experiences among family members of a deceased cancer patient.

Method. Data in this report come from 19 African Americans who experienced the loss of a family member to cancer. A qualitative descriptive design was used with criterion sampling, open-ended semistructured interviews, and qualitative content analysis.

Results. Participants made sense of the death of their loved one using the following five themes: *Ready for life after death; I was there; I live to honor their memory; God's wisdom is infinite; and God prepares you and brings you through.* These five themes are grounded in conceptualizations of spirituality as connectedness to God, self, and others.

Significance of results. Our findings support the results that even during bereavement, spirituality is important in the lives of African Americans. African American family members might struggle with issues related to life after death, their ability to be physically present during end-of-life care, and disentangling beliefs around God's control over the beginning and ending of life. The findings in this report can be used to inform healthcare providers to better support and address the needs for support of African American family members during end-of-life and bereavement experiences.

Introduction

African Americans experience a greater burden from cancer with higher levels of advanced stage disease and mortality rates when compared to other US racial/ethnic groups (American Cancer Society, 2016). In 2012, the death rate for all cancers combined was 24% higher in black men and 14% higher in black women than in white men and women (American Cancer Society, 2016). The greater burden from cancer also influences a lower life expectancy experienced among African Americans when compared with whites (ie, 72.3 vs. 76.7 years for men and 78.4 vs. 81.4 years for women; American Cancer Society, 2016). Family members of cancer patients also suffer with psychological distress reaching moderate to severe levels (Gotze et al., 2016; Ullrich et al., 2017), a lack of social support (Busolo & Woodgate, 2015; Kuo et al., 2017), and other negative feelings associated with grief (Nappa et al., 2016). In addition, there might be concerns related to issues around the quality of care delivered (Rhodes et al., 2012), including the management of pain and suffering (Devik et al., 2016; Kim et al., 2017).

Research examining end-of-life and bereavement experiences among African American cancer patients and their family members has generally focused on issues related to treatment decision-making (Smith-Howell et al., 2016), hospice use (LoPresti et al., 2016; Sharma et al., 2015), and the quality of care delivered (Rhodes et al., 2012). Although limited, evidence suggests that family members with strong religious values and beliefs are likely to have improved communication and trusting relationships with healthcare providers and therefore less decisional regret (Smith-Howell et al., 2016) and less distress during discussions focused on palliative and hospice care (Johnson et al., 2016). However, the end-of-life and bereavement experience among African Americans is best understood within the context of their religious culture and the beliefs embedded in that tradition.

Spirituality has provided a means for African Americans to communicate their struggles and fears to God, to express their belief in the promise of a future life free of pain and suffering, to encourage each other during adversity, and to maintain a positive sense of self (Cone,

2002; Raboteau, 1978). Moreover, African Americans affiliated with traditional Black Protestant traditions tend to be grounded in certain religious beliefs (Pew Research Center, 2016). For example, members of this faith believe with absolute certainty that God exists, rely on their religion as a source of guidance, believe that scripture passages are the word of God that should be taken literally, and believe in the existence of heaven and hell (Pew Research Center, 2016). Thus, with a life-threatening cancer diagnosis, this strong religious culture may emphasize beliefs in miracles and physical healing (Campbell et al., 2011; Hamilton et al., 2013a; LoPresti et al., 2016) and ultimately that God gives life and therefore has the final say in when life ends (Hamilton et al., 2013a; LoPresti et al., 2016).

Research that focuses on the influence of the strong cultural religious tradition on the end-of-life and bereavement experience from the perspectives of African American family members is limited. In comparison to whites, African Americans are more likely to believe in God and life after death in heaven (Pew Forum, 2016), a place that is free of pain and suffering (Cone, 2002). Yet, in comparison to whites, African Americans are less likely to use palliative care (Hazin & Giles, 2011) and more likely to request care in a hospital setting (Campbell et al., 2011) that is aggressive in spite of the burden placed on families (Johnson et al., 2008; LoPresti et al., 2016; Wicher & Meeker, 2012). This competing reality of the end-of-life care and the cultural tradition of relying on one's religion and spirituality is likely a great source of conflict and distress among African Americans. The findings in this report will contribute to an understanding of the ways in which African American family members make sense of the death of a loved one from cancer and the ways in which healthcare providers may support this population during times of grief and bereavement.

Methods

In this report, we used a qualitative descriptive design including criterion sampling, open-ended semistructured interviews, qualitative content analysis (Hsieh & Shannon, 2005), and quantitative descriptive analysis (Tabachnick & Fidell, 2013). Approval for this study was obtained from the Institutional Review Board of the University of North Carolina at Chapel Hill.

Participants

The interviews included in this report are from 19 African American men and women residing in the southeastern United States. To be eligible, participants must have been African American ethnicity by self-report, at least 18 years old but younger than 89 years of age, and had the experience of the death of a family member attributed to cancer. Participant interviews for this report were drawn from a larger sample that targeted participants with known religious affiliations and therefore likely to use religious practices in their daily lives.

Procedures

The first author conducted all participant interviews. Interviews lasted from 15 to 45 minutes and were conducted in the privacy of participants' homes. Participants were given a \$30 gift card for each interview. All interviews were conducted between 2013 and 2014.

In the parent study, participants were asked to talk about whether and how they used religious songs, scriptures, and prayers

in response to stressful life events such as the death of a family member or their own experience with a life-threatening illness. All participants were asked to respond to three open-ended questions: "Can you recall a time in your life that was particularly stressful for you?" "Tell me about a religious song, scripture, or prayer that helped you during that time," and "Tell me how that song, scripture, and/or prayer helped you during that time." Follow-up questions included: "Can you recall how you were feeling when you used that song or scripture, or prayer?" and "Tell me why you used that particular song, scripture, or prayer." The focus of this report is on ways in which bereaved family members responded to follow-up questions regarding the death of a family member and their use of spirituality to make sense of their loss.

Strategies to Enhance Rigor

All interviews were conducted in the privacy of participants' homes with only the interviewee and first author present. Participants were encouraged to freely express issues and experiences related to their self-identified stressful life event and spirituality. Interviews were audio- or videotaped and later transcribed verbatim, with the first author and a research assistant reviewing each transcript for accuracy. Member checking was conducted with members of the target population and clergy during the process of data collection and drafting of this report to validate the interpretation of findings, generation of themes, and accuracy of conclusions. The first and second authors independently read selected quotes related to bereavement from transcripts for the purpose of arriving at clarity and agreement of definitions of emerging themes for the categories related to making sense of loss. These coded themes were uploaded into SPSS v. 24 and quantitative methods were used to determine the frequency of themes occurring among these participants. Intercoder reliability was conducted using data coded from a random sample of 10 (53% of the total sample) transcripts with the first and fourth authors. Cohen's kappa was calculated and deemed moderate to perfect (0.57, 0.61, 0.77, 1.00, 0.77; Burla et al., 2008).

Data Analysis

To content-analyze the data, a table was initially constructed to organize each participant's responses by category of text reported that related to thoughts and feelings associated with his or her experience with the patient before and after death. These categories were labeled using texts drawn from religion, theology, and from the participants' narrative responses.

Results

Participant Characteristics

The 19 participants identified as having the stressful event of a family member death from cancer were an average age of 53.6 years ($SD = 20.7$). Participants were primarily women ($n = 16$, 84.2%), married ($n = 8$, 42.1%), had completed high school ($n = 17$, 89.0%), were employed ($n = 8$, 42.1%), affiliated with a Baptist Church ($n = 10$, 52.6%), and lived in rural areas ($n = 12$, 63.2%; Table 1).

Type of Cancer Diagnoses Reported

Participants most frequently ($n = 6$, 32%) reported that the doctor told them the patient's diagnosis was just "cancer." Specific type

Table 1. Demographic characteristics of study participants

Characteristics	Cancer survivors (N = 19)
Age, mean (SD)	53.6 (20.7)
Female, n (%)	16 (84.2)
Rural, n (%)	12 (63.2)
Marital status, n (%)	
Married	8 (42.1)
Widowed	4 (21.1)
Divorced	5 (26.3)
Never married	2 (10.5)
Education, n (%)	
Highschool	2 (10.6)
High school degree	5 (26.3)
Partial college	5 (26.3)
College degree	5 (26.3)
Graduate/professional	2 (10.5)
Employment status, n (%)	
Student	1 (5.3)
Full-time/part-time	8 (42.1)
Retired	6 (31.6)
Quit because of health	4 (21.1)
Religious affiliation, n (%)	
Baptist	10 (52.6)
Methodist	3 (15.8)
Catholic	1 (5.3)
Holiness	1 (5.3)
Nondenominational	4 (21.1)

cancer diagnoses included: pancreatic ($n = 3$, 16%), breast ($n = 3$, 16%), lung ($n = 2$, 11%), esophageal ($n = 1$, 5%), brain ($n = 1$, 5%), leukemia ($n = 1$, 5%), and stomach ($n = 1$, 5%). This report includes responses from two family members of one deceased patient.

Relationship to Family Member

Participants also reported their relationship to the individual that died. Relationships to deceased family members included a mother ($n = 7$, 37%), sister ($n = 3$, 16%), husband ($n = 2$, 11%), father ($n = 1$, 5%), grandmother ($n = 1$, 5%), grandfather ($n = 1$, 5%), brother ($n = 1$, 5%), aunt ($n = 1$, 5%), and cousin ($n = 1$, 5%). In the next section, we discuss the themes that emerged from the interviews and the frequency with which these themes occurred. In the following sections, we illustrate with brief quotations from participants of how they made sense of the loss of their family member.

Making Sense of the Loss Themes

The 19 participants included in this report were family members that discussed the ways in which they made sense of their loss within the context of their spiritual beliefs. The themes that emerged from these interviews and the frequency with which

they occurred among these 19 participants included: *Ready for life after death* ($n = 9$, 47.4%), *I was there* ($n = 8$, 42.1%), *I live to honor their memory* ($n = 8$, 42.1%), *God's wisdom is infinite* ($n = 7$, 36.8%), and *God prepares you and brings you through* ($n = 7$, 36.8%). Participants' interviews could have resulted in more than one theme.

Ready for Life After Death

Among these participants, death was believed to be a temporary state, that their loved one would transition to a future eternal life. Consistent with traditional Black Protestant religious beliefs, God has promised a heavenly home that is free of the experience of pain and suffering that may accompany advanced stage cancers. For participants in this report, it was important to have the assurance that the patient had a relationship with God and lived a life that would ensure a continued life in heaven. One 84-year-old widowed woman whose mother had died from cancer recalled the exact moment her mother died and found comfort in knowing that her mother was "ready to go home."

When my mother died I was upset about it... but mother kept saying 'I want to go home', ... and then the day that she died, I was upstairs talking to her and she said 'oh there you are' ... she had been wanting to see me. ...and she was telling them that she wanted to see me before she died... and I said mother if you want to go home, I will help take care of [name omitted] and I will be with [name omitted] ... and she said okay and she closed her eyes and a tear came out of her eye and she was gone. And so I was calm and peaceful after she died because I knew she was ready ...

One 49-year-old married woman talked about the deaths of her mother and sister from cancer and how she found comfort in the belief in life after death and her perspective of death as a temporary state:

... and they [others] look at the end part of it but for myself it was more of watching her transition because of my faith ... One of my favorite scriptures is John:14, *Let not your heart be troubled because if you believe in God, believe in me, He says in my fathers' house are many mansions and if it were not so, He would not have told us.* And He has gone to prepare a place for us and ... He will come back and receive us and those are the promises and that is what I relied on... the belief that these things are temporal, just temporary. This is not the end...

I Was There

Being physically present during the death was important. Participants talked about being there before the patient's death and feeling helpful or helpless. When able to "be there," family members sang hymns and recited Bible verses to their loved one. On the other hand, participants not physically present during the transition thought about their absence in ways that gave them inner peace. One 54-year-old divorced woman talked about being there and helping to distract her dying mother with a hymn when she was in pain:

Blessed Assurance is one of the songs when my mother was dying of cancer, and she was in so much pain. We would sing—she, and I, and my sister would sing *Blessed Assurance* and that song would bring her so much comfort. That was her favorite hymn.

The second quote from a 62-year-old married woman is a reminder of how some individuals might be fearful of being in the presence of the dying.

... at least I was able to be there to do what I could but especially to be there 'cause I seen the time when I wasn't able to be there 'cause I was afraid to be around sick people, really scared to be around sick people.

Although some participants were physically there and able to help, others described a sense of helplessness when their loved one was dying. They were physically there, a witness to the suffering, yet not able to do anything. One 62-year-old married man described his most stressful life event of watching his father die of a cancer that was incurable; no treatment was available. He had this to say:

The most stressful event that I have suffered was being with my father when he died, watching him die, and knowing there was nothing nobody could do to help him ... cancer had set in throughout much of his body, and there was nothing they could do for him. And today's time they might have been able to help him some, but at that time, the medical field was not that far advanced, so they had, there was nothing they could do but send him back to the house and watching him suffer like that, it was hard on me ...

I Live in Honor of Their Memory

Participants spoke of ways in which the death of their loved one was a motivator for them to continue with life, to achieve some life goal, or live a better life in honor of the deceased patients' memory. A commitment to a better life in honor of the deceased was possibly a form of spirituality as transpersonal connectedness; living a life according to God's purpose (Reed, 1992). One 25-year-old man made sense of his loss through a belief that his grandfather and God would want him to continue living life to the fullest.

We were close... He [the grandfather] was always supportive, always caring, he showed me a bunch of love. I learned a lot from him, a lot of things by communicating; a lot of things by observation... He lived his entire life so I can't have this dark cloud over my life which I hope to live to the fullest extent that he did, if not even further. I can't wallow in the past or in sorrow because I lost a loved one. I got to keep living because that's what he would want me to do. That's what God wants us to do you know.

Living in honor of their memory was also a form of spirituality and intra- and interpersonal connectedness to self and the deceased (Reed, 1992). That is, participants found meaning and a sense of inner purpose through a life lived in honor of the deceased loved one (Reed, 1992). An 18-year-old woman and first-year college student recalled her efforts to excel in high school as a way to remember her aunt:

Well, I just remember being really, really sad about [name omitted], I just felt kind of depressed about that. But that kind of gave me the drive to do better in school, because [name omitted] always called me "brainiac" or "smarty pants" or something along those lines, an endearment. It was kind of disguised as an insult. So I was like 'You know what, I'm going to do really good,' so ... I decided I wanted to be valedictorian ... I remember when I got it ... and I was like 'Yep, I did it'.

In another example of intra- and interpersonal connectedness, participants carried out the patient's legacy through assuming family, church, or work roles of the deceased. A 62-year-old married man, who was 15 or 16 when his father died, assumed the role of "man of the house" when his father died.

I knew that I had to get out and help provide for the household. At that time there wasn't much jobs for women especially black women at that

time, and there wasn't that much money to be made, and when I did get a job, I got a job in a factory, and the minimum wage at that time, I think was three dollars and hour, and that was big money and so I did what I did to help provide for the family.

God's Wisdom Is Infinite

Participants had faith in God's omnipotence, absolute power, and limitless knowledge. Participants may have been socialized in their formative years to believe that "everything happens for a reason" and that when death happens "God knows best." One 25-year-old single man described this reasoning when talking about the death of his grandfather from pancreatic cancer.

... But I always kind of have it ingrained in the back of my head, God doesn't make mistakes. I was told at a young age that everything happens for a reason. My parents were always telling me 'don't worry about things you can't change because if you could change it you wouldn't have to worry about it.' So that kind of gave me peace. Not immediately but after a while it kind of gave me peace knowing that hopefully he made it to a better place and this was something that was out of my control.

Acceptance in God's wisdom to know what is best was not always immediate. One 36-year-old divorced woman articulated her initial anger at God for taking her mother from her despite her prayers for healing. This participant described how over time, she came to accept that her mothers' death was a part of God's plan.

I would be in her hospital room and I'm like God heal my mom. ... you get to bargaining with God, I'm like if you heal my mom I'm going to walk straight. I'm going to do this, I'm going to do that. When she died I was devastated and angry because I'm like God I told you I was going to give my life to you if you would heal her but she's gone and I'm here and I'm alone... But in regards to the healing I know now to be absent from the body is to be present with the Lord. And I know now healing comes in a lot of forms and fashion and sometimes healing is on the other side. Sometimes you don't receive healing here on this Earth. Sometimes your healing doesn't come until you are present with God... Because He took her, He healed her... I didn't understand it [initially] because I thought it [healing] was going to be with her being here [on earth].

God Prepares You and Brings You Through

Participants spoke of their faith and trust that God would be there to get them through the pain of their loss and keep them going. Participants relied on God for someone to talk to because some family, friends, and fellow church members could be judgmental and not understand the pain of their loss. Some participants also believed that earlier traumatic events prepared them for the current loss. These participants believed that if God was there to support them through previous adversities, then He would do it again. One 65-year-old widow described an earlier stressful life event that prepared her for the death of her sister from breast cancer:

You know, they always say that you need somebody to talk to, but I guess my thing is that I don't trust people enough to spill my guts... but I can tell Jesus. No matter what I can tell Him, and He is going to understand, and that He is not going to judge me about what I'm thinking or what I say at that time... so it's like when [name omitted] was in prison, and I had to raise the kids by myself. I didn't understand why I was alone. But then after he [name omitted] died I could understand that He [God] was just preparing me for what was going to happen later on in life. So now I can just go through because I'm used to being on my own.

Discussion

The findings of this report extend what is known of ways in which family members of the deceased African American cancer patient use religious beliefs and spirituality to make sense of end-of-life and bereavement experiences. A consideration for: *Ready for life after death; I was there to help; I live to honor of their memory; God's wisdom is infinite; and, God prepares you and brings you through*, enabled these participants to make sense of their loss through their religious beliefs and spirituality, turning a potentially negative event into one that was positive and mental health promoting.

Ready for life after death exemplified the importance of participant's spirituality as a future life with God and, therefore, temporal state of death. Participants found peace and comfort in knowing and accepting that the deceased was "ready to go home," had a relationship with God, and had the assurance that life was possible after death in Heaven. African Americans affiliated with historically Black Protestant traditions believe with certainty that God exists and in the existence of an afterlife in Heaven (Pew Research Center, 2016). In other studies, African American family members have engaged in religious activities such as singing hymns, reading Biblical scriptures, and praying as a way of preparing for the patients' death, but participation in these religious activities also provided the assurance that the patient was "ready" for life after death in Heaven (Hamilton et al., 2013a, 2013b; Johnson, 1993). A readiness to "go home" is also consistent with reports on patients with incurable cancers whose desires at the end of life were to be at peace with God, for their families to be prepared for their death, and to participate in religious activities (Delgado-Guay et al., 2016; Hampton et al., 2007). Historically, African Americans have adopted a spirituality that emphasizes the belief in a life after death where deceased loved ones would be seen again (Jones, 1993; Raboteau, 1978; Walker, 1979). Perhaps knowing the deceased was "ready to go home" was important because the home of reference is Heaven, a place where loved ones would be seen again (Johnson, 1993). However, the majority of African Americans affiliated with historically Black Protestant traditions also believe Heaven is a place rewarded to the faithful; where good people go (Jones, 1993; Raboteau, 1978; Walker, 1979). Therefore, given this belief, it is not surprising that family members would be concerned with knowing that their loved one had a relationship with God and indeed "ready to go home."

The theme *I was there* exemplified a connectedness interpersonally (to the deceased and other family members) and possible obligation to help one another in need, which is another dimension of spirituality that enabled these participants to make sense of their loss (Hamilton & Sandelowski, 2003; Lawson & Thomas, 2007; Young et al., 2015). In palliative care research, inpatients with incurable cancers have expressed the desire for their family's presence, to say goodbye, but not be a burden (Delgado-Guay et al., 2016). However, the findings from this report suggest the dynamic, governing nature through which these obligations are fulfilled. As these participants suggest, their ability to "be there to help" might be heavily influenced by the patient's desires. Patients ultimately decide when and to whom they will disclose information about their illness (Hamilton et al., 2010). Patients will also make requests for other family members to continue family, work, or social roles or continue individual life goals. In other research, African American cancer patients have preferred to not be in the presence

of family or friends who treated them with pity or as if they were lepers (Hamilton et al., 2010). Participants in this report remembered that their presence or absence was desired by the deceased or at the request of other family members. Ultimately, the family members' presence was dictated by the deceased patient's wishes or consistent with overall family needs and values.

Although the finding of *Living in honor of their memory* is not particularly novel, participants found a way to honor the deceased through acting on educational and life goals. Excelling in school, starting a business, and making improvements to one's character on a spiritual level were evident in these participant interviews. Our findings are consistent with other research conducted among cancer survivors in which positive outcomes were in the form of enhanced social support (Litzelman et al., 2017). Cancer patient and family caregiver dyads have experienced personal growth, improved relationships, acceptance (Cheng et al., 2016; Li et al., 2017; Mosher et al., 2017), and enhanced personal strength in caregivers during bereavement (Kim et al., 2013). However, to our knowledge this is the first study to extend findings focused on finding benefit and keeping legacies of bereaved individuals after a cancer diagnosis to include excelling in educational and life goals for the family member (Foster et al., 2009; Keim-Malpass et al., 2015).

When participants trusted in *God's infinite wisdom*, they eventually came to understand and accept the timing and circumstances of their loved one's death. When trusting in God's infinite wisdom, participants let go of worries or anxieties related to the outcome. However, accepting death as part of God's will was a process that was not immediate, but that generally occurred over months or even years. During this process, participants initially questioned God and felt let down when prayers for healing were unanswered. Historical and religious literature has documented that African Americans have accepted that God is in control of all issues related to life and death; has wisdom beyond mortals and ultimately does what is best for His children (Cone, 2002; Raboteau, 1978). Moreover, African Americans affiliated with historically Black Protestant traditions tend to accept text from the Holy Bible as God's word literally and are therefore likely to accept suggestions to trust in the Lord and to have faith that He knows best (Pew Research Center, 2016).

A reliance on God to support and *Bring them through* is another dimension of spirituality and connectedness to God that is consistent with research conducted with African American elders, cancer patients, and family members (Coats et al., 2015). African American cancer patients with curable disease and their family members have described having faith that God would provide the support and necessary strength to get through the situation (Sterba et al., 2014; Torres et al., 2016). Participants in this report believed that God permitted previous tragedies that later provided the necessary strength, assurance, and perseverance through the death of their loved one (Cone, 2002). Praying for healing and strength is an important aspect of the African American cancer experience for patient and family member (Washington, 1995). However, for these participants, prayers during bereavement were a means to talk to God about their sorrows and pains. The ability to talk to God was important because support might have otherwise not been available (Washington, 1995).

An examination of interviews focused on religious practices in response to stressful life events was a useful strategy to understand the ways in which spirituality enabled family members to make sense of the loss of a loved one to cancer; however, we note a few limitations to this approach. Because the primary focus of

the original interviews was for another purpose, there is the chance that other topics specifically related to end of life and palliative care were missed. Participants in this study were not necessarily designated caregivers who likely had a different relationship with the deceased. Finally, the lack of participants that are not religiously affiliated is a limitation. However, 87% of African Americans in the United States are affiliated with Black Protestant traditions and the religious culture of those faith-based institutions (Pew Research Center, 2016).

Conclusions

Our findings support that even during bereavement, spirituality is important in the lives of African Americans. Admittedly, participants struggle with and even question their beliefs in bereavement but still hold fast to the basic belief in God and the control He has over issues related to life and death. The findings in this report can be used to inform healthcare providers to better support and address the needs for support of African American family members during end-of-life and bereavement experiences.

References

- American Cancer Society (2016) Cancer facts & figures for African Americans 2016–2018. Available from <https://www.cancer.org/research/cancer-facts-statistics/cancer-facts-figures-for-african-americans.html>
- Burla L, Knierim B, Barth J, et al. (2008) From text to codings: Intercoder reliability assessment in qualitative content analysis. *Nursing Research* 57, 113–117.
- Busolo D and Woodgate R (2015). Palliative care experiences of adult cancer patients from ethnocultural groups: A qualitative systematic review protocol. *JBI Database of Systematic Reviews Implementation Reports*, 13, 99–111.
- Campbell CL, Williams IC, and Orr T (2011) Factors that impact end-of-life decision making in African Americans with advanced cancer. *Journal of Hospice & Palliative Nursing*, 41(1), 277–278.
- Cheng H, Sit JW, and Cheng KK (2016) Negative and positive life changes following treatment completion: Chinese breast cancer survivors' perspectives. *Supportive Care in Cancer*, 24, 791–798.
- Coats H, Crist JD, Berger A, et al. (2015) African American elders' serious illness experiences: Narratives of "God did," "God will," and "life is better". *Qualitative Health Research*, 27(5):634–648.
- Cone JH (2002) *God of the oppressed*. Maryknoll, NY: Orbis Books.
- Delgado-Guay MO, Rodriguez-Nunez A, De la Cruz V, et al. (2016) Advanced cancer patients' reported wishes at the end of life: A randomized controlled trial. *Supportive Care in Cancer*, 24, 4273–4281.
- Devik SA, Hellzen O, and Enmarker I (2016) Bereaved family members' perspectives on suffering among older rural cancer patients in palliative home nursing care: A qualitative study. *European Journal of Cancer Care*, 26(6).
- Foster TL, Gilmer MJ, Davies B, et al. (2009). Bereaved parents' and siblings' reports of legacies created by children with cancer. *Journal of Pediatric Oncology Nursing*, 26, 369–376. d
- Gotze H, Braehler E, Gansera L, et al. (2016). Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *European Journal of Cancer Care*. Epub ahead of print 17 Nov 2016.
- Hamilton J and Sandelowski M (2003) Living the golden rule: Reciprocal exchanges among African Americans with cancer. *Qualitative Health Research*, 13, 656–674.
- Hamilton JB, Moore AD, Johnson KA, et al. (2013a) Reading the Bible for guidance, comfort, and strength during stressful life events. *Nursing Research*, 62(3), 178–184.
- Hamilton JB, Moore CE, Powe BD, et al. (2010) Perceptions of support among older African American cancer survivors. *Oncology Nursing Forum*, 37, 484–493. doi: 10.1188/10.ONF.484-493
- Hamilton JB, Sandelowski M, Moore AD, et al. (2013b) "You need a song to bring you through." The use of religious songs to manage stressful life events. *Gerontologist*, 53, 26–38.
- Hampton DM, Hollis DE, Lloyd DA, et al. (2007) Spiritual needs of persons with advanced cancer. *American Journal of Hospice and Palliative Medicine*, 24(1), 42–48.
- Hazin R and Giles CA (2011) Is there a color line in death? An examination of end-of-life care in the African American community. *Journal of the National Medical Association*, 103, 609–613.
- Hsieh HF and Shannon SE (2005) Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277–1288.
- Johnson CH (1993) *God struck me dead: Voices of ex-slaves*. Cleveland, OH: The William Bradford Collection from the Pilgrim Press.
- Johnson KS, Kuchibhatla M, and Tulskey JA (2008) What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatrics Society*, 56, 1953–1958.
- Johnson J, Hayden T, True J, et al. (2016) The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members. *Journal of Palliative Medicine*, 19(2), 143–148.
- Jones AC (1993). *Wade in the water. The wisdom of the spirituals*. Maryknoll, NY: Orbis Books.
- Keim-Malpass J, Adelstein K, and Kavalieratos D (2015) Legacy making through illness blogs: Online spaces for young adults approaching the end-of-life. *Journal of Adolescent and Young Adult Oncology*, 4(4), 209–212.
- Kim HM, Hwang SW, and Hwang IC (2017) Actual and recalled perceptions of the end-of-life care situations among bereaved families of cancer patients: A longitudinal pilot study. *Psychooncology*. Epub ahead of print 14 Feb 2017.
- Kim Y, Carver CS, Schulz R, et al. (2013) Finding benefit in bereavement among family cancer caregivers. *Journal of Palliative Medicine*, 16, 1040–1047.
- Kuo SC, Chou WC, Chen JS, et al. (2017). Longitudinal changes in and modifiable predictors of the prevalence of severe depressive symptoms for family caregivers of terminally ill cancer patients over the first two years of bereavement. *Journal of Palliative Medicine*, 20, 15–22.
- Lawson EJ, and Thomas C (2007) Wading in the waters: Spirituality and older black Katrina survivors. *Journal of Health Care for the Poor and Underserved*, 18, 341–354.
- Li Q, Lin Y, Xu Y, et al. (2017) Construct validity of the 17-item Benefit Finding Scale in Chinese cancer patients and their family caregivers: A cross-sectional study. *Supportive Care in Cancer* 25(8):2387–2397.
- Litzelman K, Blanch-Hartigan D, Lin CC, and Han X (2017). Correlates of the positive psychological byproducts of cancer: Role of family caregivers and informational support. *Palliative Supportive Care*, 1–11.
- LoPresti MA, Dement F, and Gold HT (2016) End-of-life care for people with cancer from ethnic minority groups: A systematic review. *American Journal of Hospice & Palliative Care*, 33, 291–305.
- Mosher CE, Adams RN, Helft PR, et al. (2017). Positive changes among patients with advanced colorectal cancer and their family caregivers: A qualitative analysis. *Psychology Health*, 32, 94–109.
- Nappa U, Lundgren AB, and Axelsson B (2016) The effect of bereavement groups on grief, anxiety, and depression: A controlled, prospective intervention study. *BMC Palliative Care*, 15, 58.
- Pew Research Center (2016) *A religious portrait of African-Americans*. Available from <http://www.pewforum.org/religious-landscape-study/>.
- Raboteau AJ (1978) *Slave religion. The "invisible institution" in the antebellum south*. New York: Oxford University Press.
- Reed PG (1992) An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing & Health*, 15(5), 349–357.
- Rhodes RL, Xuan L, and Halm EA (2012) African American bereaved family members' perceptions of hospice quality: Do hospices with high proportions of African Americans do better? *Journal of Palliative Medicine*, 15, 1137–1141.
- Sharma RK, Cameron KA, Chmiel JS, et al. (2015) Racial/ethnic differences in inpatient palliative care consultation for patients with advanced cancer. *Journal of Clinical Oncology*, 33, 3802–
- Smith-Howell ER, Hickman SE, Meghani SH, et al. (2016) End-of-life decision making and communication of bereaved family members of African Americans with serious illness. *Journal of Palliative Medicine*, 19, 174–182.
- Sterba KR, Burris JL, Heiney S, et al. (2014) "We both just trusted and leaned on the Lord." A qualitative study of religiousness and spirituality among

- African American breast cancer survivors and their caregivers. *Quality of Life Research*, **23**, 1909–1920.
- Tabachnick BG and Fidell LS** (2013) *Using multivariate statistics*, (6th ed. Boston: Pearson Education.
- Torres E, Dixon C, and Richman AR** (2016) Understanding the breast cancer experience of survivors: A qualitative study of African American women in rural eastern North Carolina. *Journal of Cancer Education*, **31**, 198–206.
- Ullrich A, Ascherfeld L, Marx G, et al.** (2017) Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC Palliative Care*, **16**(1), 31.
- Walker WT** (1979) *Somebody's calling my name. Black sacred music and social change*. Valley Forge, PA: Judson Press.
- Washington JM** (1995) *Conversations with God: Two centuries of prayers by African Americans*. New York: HarperCollins.
- Wicher CP and Meeker MA** (2012) What influences African American end-of-life preferences? *Journal of Health Care for the Poor and Underserved*, **23**, 28–58.
- Young WC, Nadarajah SR, Skeath PR, et al.** (2015) Spirituality in the context of life-threatening illness and life-transforming change. *Palliative & Supportive Care*, **13**, 653–660.