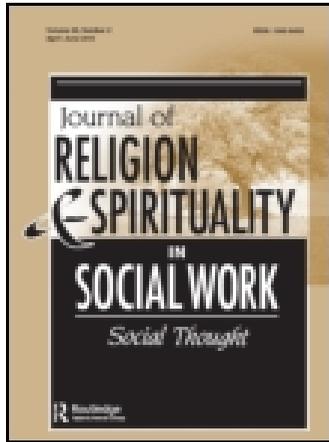


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The Role of Spirituality at End of Life in Nova Scotia's Black Community

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The Role of Spirituality at End of Life in Nova Scotia's Black Community

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This study used qualitative in-depth interviews and focus groups to examine the role of spirituality at end of life (EOL) in Nova Scotia's Black community. We also examined data from another research project that examined health issues in the Black community. The purpose of this research was to examine the issue of spirituality from the perspective of family caregivers, and spiritual leaders who have cared for someone who has died. More specifically, we explored how spirituality is expressed and how it serves as a coping mechanism during times of suffering and hardship at the EOL. Principal findings include the need for health providers to be aware of the spiritual needs of families of African descent and to include spirituality as a part of the EOL care plan.

KEYWORDS *spirituality, end of life, African Canadian, palliative care*

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There is a dearth of research examining end of life (EOL) care among African Canadians. Based on a review of the literature, two studies conducted by the current research team are the only studies examining EOL care among African Canadians (Maddalena et al., 2010; Maddalena et al., 2013). Findings from the first two projects highlighted the important role spirituality plays at EOL in the province's Black communities, and were the motivation for the current study.

Spirituality and religion are imbedded in all cultures and influence the lives and well-being of many people (Puchalski, 2001). Religion is often viewed in terms of systems, social institutions that are either joined or organized by individuals who share the same beliefs, traditions and rituals (Dyson, Cobb, & Forman, 1997; Emblen, 1992; Strang, Strang, & Ternestedt, 2002). While religion is characterized by its boundaries, spirituality is a "personal search for meaning and purpose in life which may or may not be related to religion" (Tanyi, 2002). Spirituality is also the acknowledgment of a nonmaterial force that permeates all affairs, human or nonhuman (Mattis & Jagers, 2001 as cited in Polzer, 2007).

While there is no extant literature documenting the role of spirituality at EOL in the African Canadian communities, there is a body of literature documenting the importance of spirituality and religion in the African American communities (Este & Bernard, 2006; Giger, Appel, Davidhizar, & David, 2008; Holt, Wang et al., 2011), particularly in the area of terminal illness (Gallia & Pines, 2009) and coping with cancer (Gallia, Pines, 2009).

Spirituality plays a defining role in Black culture and is viewed as a positive means of coping with traumatic life experiences (Holt, Schulz et al., 2011; Holt, Wang et al., 2011). While there may be common cultural features between African Canadians and African Americans at EOL and accessing health services, the African American experience is different from that of African Canadians, primarily because of different access to health and social support systems (public vs. private care).

In the lives of people of African descent, the church has been identified as an important institution. The church is viewed as the center of social life, communication, and a source of strength for families of African descent (Blake & Darling, 2000). It also has been named as a significant resource in the ongoing fight against racism (Lewis-Coles & Constantine, 2006; Acton & Lloyd, 2004). In addition, spirituality is identified as significant for people of African descent (Este & Bernard, 2006; Heath, 2006; Mattis, 2002). For example, Este and Bernard assert that:

Spirituality serves as a source of strength, is used as a coping strategy in a society where African Nova Scotians continue to experience racism and discrimination and, finally, is an important aspect of the health and well being of this group. (2006, p. 16)

Beagan, Etowa, and Bernard (2012), in their study of the racism-related experiences of 50 midlife African-heritage women living in Nova Scotia, found that spirituality was frequently cited as a coping strategy for dealing with racism-related stress. Similarly, Banerjee and Pyles (2004) in their study with African American women on welfare note spirituality as a way of coping with and surviving struggles related to experiencing racism in their lives.

Spirituality is also gaining attention in health care as spirituality/religion plays a vital role in the lives of patients recovering from life threatening illnesses and those who are in palliative or EOL care. Spirituality and spiritual care may have special consequence at the EOL as patients increasingly ask questions and search for meaning in their struggles and pain (Edwards, Pang, Shiu, & Chan, 2010).

This study explores the levels of importance attributed to spirituality and religion in the lives of African Canadians living in Nova Scotia. While health care in Canada does not gather information on race and ethnicity (James et al., 2010; Varcoe, Browne, Wong, & Smye, 2009), the need for such data is gaining prominence. This is especially relevant in Nova Scotia, where African Canadians have had a presence since the early 1600s (Pachai, 1990). Since their early arrival, African Nova Scotians have lived with the effects of widespread systemic and institutionalized racism. Evidence of this can be found in their geographic segregation and marginalization (Pachai, 1990), the history of segregated education, and the lack of access to mainstream services (Este & Bernard, 2006; Etowa, Weins, Bernard, & Clow, 2007; James et al., 2010), including health care (McGibbon & Etowa, 2009). This study focuses on the importance of spirituality to African Canadians and the role of spirituality and religion in the lives of African Nova Scotian family caregivers and spiritual leaders involved in EOL care.

LITERATURE REVIEW

The Role of Spirituality and Religion in EOL

The knowledge that a person is dying may evoke feelings of anger, fear, grief, depression, guilt, denial, and loss of hope and meaning for terminally ill patients and their loved ones. For many, spirituality helps patients and their families in palliative and EOL care cope with the stresses associated with illness, and find meaning in the midst of pain and suffering. Spirituality may be dynamic to patients' understanding of the illness, and spiritual or religious beliefs may affect the decisions patients make about their health, illness and the treatment choices they make (Pulchalski, 2001). Having a sense of meaning, peace, and purpose benefits patients in psychological distress, and helps them tolerate severe physical pain symptoms (Breitbart, Gibson, Poppito, & Berg, 2004). Spirituality also provides patients with a sense of meaning that improves their quality of life in spite of their pain and struggles (Breitbart et al., 2004).

Spirituality also helps patients with terminal illness cope with pain, suffering, and loss and be more accepting that there is no cure. For instance, patients with advanced cancer who found comfort from their religious and spiritual beliefs were more satisfied with their lives, happier, and had diminished pain (Yates, Chalmer, St. James, Follansbee, & McKegey, 1981). The spiritual beliefs of patients therefore help them cope better with their illness and with facing death (Roberts, Brown, Elkins, & Larson, 1997). It also helps family members cope with the illness and death of their loved one.

Religion and spirituality also help in personal growth and healing of individuals and this often occurs at the EOL. While terminal illness is perceived as negative or devastating, it becomes a time for spiritual reflection for some people. Although spiritual growth and healing do not diminish the pain and suffering experienced by patients who are terminally ill and their families, it helps patients and their families to reflect and find spiritual healing (Knight & von Gutten, 2004). Dependency, loss, fear, and suffering may cause many persons to have a reawakening by turning (or returning) to their religious or spiritual practices for comfort and strength. Spirituality therefore gives patients and family members another opportunity to reconcile with one another, connect, or reconnect with God and seek spiritual, psychological or physical healing.

Separating the role of religion and spirituality, (Beagan, Etowa, & Bernard, 2012) state that “while church communities may provide a sense of connection, they may also leave some feeling excluded. The sense of connectedness attached to spiritual life, however is more internal” (p. 4). Bernard (1999) makes a similar distinction, noting that organized religion can sometimes cause stress for those who feel alienated from the church for some reason, whereas one’s spirituality is more innate. For the majority of participants in her study with Black men, Bernard asserts that spirituality was identified as the essence of their survival.

METHODS

This study was conducted in two phases. Phase one was a secondary analysis of original quantitative data collected in the Racism, Violence and Health (RVH) Study (2002–2008), which was funded by the Canadian Institutes of Health Research (CIHR): Institute of Gender and Health. Phase two was a qualitative study with in-depth interviews and focus groups to collect data from pastors and family caregivers, funded by CIHR Interdisciplinary Capacity Enhancement Grant Network for End of Life Studies. Both studies were granted ethical approval from Dalhousie University Research Ethics Board.

In this first phase of our study we conducted secondary analysis of survey data collected from the RVH project (2006), in particular the sections that

examined the perceptions and experiences of both global and race-related stress in the indigenous and immigrant populations in African Canadian communities in Halifax, Toronto, and Calgary. It investigated the influence of witnessing and surviving violence, including the violence of racism, on the health and well-being of individuals, families, and community members. While examining the impact of racism and coping mechanisms among African Canadians, participants provided information on the influence of spirituality in their lives. A total of 900 participants responded to the statement: "My culture-based spirituality is the strongest influence in how I live my life." The 900 respondents included 300 members of the Halifax Black community, 300 members of the Toronto Black community, and 300 members of the Calgary Black community.

This was a mixed methods research program that included a survey (900 participants, 300 in each site), qualitative interviews (120 participants, 40 in each site), 2-year microethnographies (six young Black men, two in each site), and annual Black community forums and smaller community meetings in each site. Using a survey developed by the research team, a 90-min face-to-face questionnaire was administered by trained members of diverse Black communities to other community members. The questionnaire included a significant number of demographic questions, standardized instruments that address perceptions of general health status, the SF-12 General Health Survey (Ware, Kosinski, & Keller, 1996), global stress (the Perceived Stress Scale; Cohen, Kamarck, & Mermelstein, 1983) and racism-related stress (Harrell, 1997, 2000), as well as project-developed scales focusing on responses to racism scale, violence, and immigration. The data entry and analysis used the most recent version of the Statistical Package for the Social Sciences. The data was entered twice, once each by two different research assistants, then compared, and the discrepancies corrected. Based on origin, participants in the RVH project were classified into three groups: Caribbean, Canadian Black, and African. Our secondary analysis of this quantitative survey data was on the responses to the statement: "My culture-based spirituality is the strongest influence in how I live my life." By culture-based spirituality, we mean culturally specific spirituality grounded in an African centered reality.

The second phase of the study used qualitative research methods, specifically in-depth, semistructured interviews and focus groups to collect data from two groups: (a) key stakeholder interviews with pastors in the African United Baptist Association (AUBA) churches and (b) focus groups with family caregivers who have cared for someone who has died. The research question we sought to answer was: What role does spirituality play in the lives of African Nova Scotians (caregivers) as they deal with EOL of a loved one? In addition we hoped to more fully understand the roles and perceptions of pastors and deacons who minister to patients and their families as they face terminal illness and death, regarding the role spirituality plays in that process.

This project used naturalistic inquiry to engage family caregivers and key informants in Nova Scotia's Black communities in an exploration of issues related to spirituality and palliative and EOL care. Naturalistic inquiries are based on a social constructionist epistemology and the research is conducted in natural settings. Typically the researcher and participant are interactive and interconnected and thus the results of the research are a joint initiative.

We understand focus groups to be a form of group interviewing. Fontana and Frey (2000) describe focus groups as an ideal method for collecting qualitative data where a particular phenomenon is of interest to the researcher. In this case the phenomenon of interest is the process of care giving for a loved one with terminal illness and the role their spirituality played for them as caregivers and the role it played for their loved one when they were alive. Group interviews have several advantages, including providing an avenue to access a rich source of data, providing a means by which data can be triangulated with other means of data collection, and aiding in recall. In addition, the "group process" can aid in problem solving and strategy development to inform policy change.

Inclusion criteria for key stakeholders was that they be pastors and deacons who were members of one of the AUBA churches in Halifax Regional Municipality; Inclusion criteria for focus group participants (family caregivers) were: (a) they must have been a primary caregiver for someone who has died from a terminal illness (in the past 5 years, but not less recent than 6 months) and (b) they must be African Canadian. In this study a "family caregiver" was considered someone who was not a paid caregiver, and could be a relative, close friend, or community member.

The inclusion criteria were used because our study objectives focused on the African Canadian experience of spirituality at EOL. We selected the time period for when a caregiver had provided care for someone who had died based on the following: 5 years being a reasonable time when specific memories regarding the EOL period would still be remembered with some degree of accuracy. The period of "not less recent than six months" was selected because it was felt that discussing the EOL period of a recently deceased loved one may be too distressing for the caregiver.

Data Analysis

Consistent with naturalistic inquiries (Lincoln & Guba, 1985) the stories of the participants, their experience and wisdom, were shared with the research team and we, in turn, reflexively interpreted these experiences. Specifically, we analyzed the data using thematic analysis (Coffey & Atkinson, 1996).

Each focus group interview and key informant interview was audio taped and transcribed verbatim. Transcripts were coded manually by the research team to identify dominant themes and novel narratives. Team meetings were held to discuss our individual coding of the transcripts. Differences

in coding and analysis were discussed and resolved through consensus. The data from the key informant interviews and focus group interviews—their stories and beliefs—were examined through the lens of Black culture. The researcher's "insider" knowledge (Acker, 2001) of Nova Scotia's Black communities figured prominently in the analysis of the data. We hired a community researcher, someone who was recognized as a community leader, to conduct the key informant interviews and focus group interviews and participate in the data analysis process. The research team identified the importance of having a local community leader in our previous studies, a practice that has been successfully used elsewhere (Etowa et al., 2007). All members of the research team, including the community researcher are African Canadian with the exception of Maddalena.

Participant Profile

There were 14 participants in this exploratory study. They ranged from 35 to 72 years of age. The average age was 58 years. Nine of the respondents were female and five were male. Five of the respondents had postsecondary education. Six had a high school certificate, and four completed some school but did not have a high school certificate. One of the respondents had no high school certificate and no postsecondary education. Ten respondents reported their relationship as married or living together. Two were divorced or separated, one was single, and one was widowed.

Of the nine respondents who were employed, three were employed full-time, one was employed part-time, one had seasonal employment, and one had both part-time and full-time employment. Of the seven respondents who were retired, two of them were employed part-time.

Thirteen respondents took care of a relative. The family members cared for included a husband, a father, a mother, two brothers, a son, a daughter, an uncle, three aunts, and a stepsister. One took care of a friend. One took care of both a neighbor and an in-law, while another took care of a friend and an in-law.

PHASE ONE RESULTS: THE RVH DATA ON SPIRITUALITY AND RELIGION

Influence and Importance of Spirituality and Religion Based on Origin/Immigration Status

As previously noted, participants in the RVH project were classified into three groups, Caribbean, Canadian Black, and African. Significant differences were noted among participants of the different origins.

The findings of the RVH project as illustrated in [Table 1](#) revealed that 23.1% participants of Caribbean origin responded "strongly false or

TABLE 1 Culture-Based Spirituality and Origin

Origin	Strongly false or mostly false	Somewhat true and false	Mostly true or strongly true	Total	Total
Caribbean (%)	23.1	19.4	57.5	372	100
Canadian Black (%)	10.6	29	60.4	283	100
African (%)	16.9	20.7	62.4	242	100
Total	17.5	22.7	59.8	897	100

Note. Racism, Violence, and Health (RVH) Project (2006).

mostly false” to the culture-based spirituality statement, 10.6% and 16.9% of the Canadian Black and African samples respectively responded the same. Moreover, 62.4% of the participants of African origin and 60.4% of Canadian Black participants responded “mostly true or strongly true” to the statement, relative to 57.7% of Caribbean participants in the sample. The percentage of participants who responded “somewhat true and false” were 19.4% for Caribbean participants, 29% for Canadian Black participants and 20.7% for participants of African origin. Combining the “somewhat true and false” and “mostly true or strongly true” responses suggest that culture-based spirituality is strongest for the Canadian Black sample (89.4%), followed by the African sample (83.1%), and Caribbean sample (76.9%).

Although significant differences have been noted among participants of the three different origins, the results show that culture-based spirituality is very strong among participants in the communities irrespective of their origin. Also, while 17.5 % of respondents from all three origins responded “strongly false or mostly false” to the statement, this does not imply that spirituality has no influence in their lives. It may be assumed that many of the participants in the sample who engage in spiritual and religious practices did not necessarily consider it culture-based (e.g., Seventh Day Adventist, United Church, and Buddhism).

Moreover, the findings of the RVH project reported that participants were engaged in either spiritual or religious practices. When participants were asked if they engaged in religious or spiritual activities “often or sometimes” during the 3 months prior to the administration of the survey, significant differences were noted in their responses. Eighty four percent of the African sample, 80% of the Canadian Black sample, and 75% of the Caribbean sample indicated that they had engaged in religious or spiritual activities often or sometimes. Thus, participants of African origin engage most in religious or spiritual practices while those of Caribbean origin are least involved in religious or spiritual practices. This shows that African Canadians of Caribbean origin are least influenced by culture-based spirituality.

Among the Caribbean sample who responded “strongly false or mostly false” to the statement “Culture-based spirituality is the strongest influence in my life,” 45% participated in spiritual or religious activities “fairly or very

often” and 9% participated “sometimes.” In regards to the Canadian Black sample that indicated the same, 37% and 17% respectively participated “fairly or very often” and “sometimes” in spiritual or religious activities. Among the participants of African origin who responded “strongly false or mostly false” to the culture-based spirituality statement, 6% and 15% of them indicated they participated in spiritual or religious activities “fairly or very often” and “sometimes” respectively. These results imply that although participants may consider other aspects (like being Black) as having the strongest influence in their lives, this does not mean that culture-based spirituality has no influence on them. Rather, they take part in religious and spiritual activities which may not necessarily have the strongest impact but still influence their lives to a certain degree.

Influence and Importance of Spirituality and Religion Based on City/Area of Residence

In response to the statement “My culture-based spirituality is the strongest influence in how I live my life,” the results of the RVH project indicated significant differences among participants who resided in the three cities, Halifax, Toronto, and Calgary, as illustrated in [Table 2](#). The results indicate that spirituality has the strongest influence in the lives of African Canadians in the Calgary communities, compared to community members resident in Halifax and Toronto, with Toronto having the least culture-based spirituality influence.

According to the RVH project results, 64% of participants living in Halifax, 49.7% of participants in Toronto and 65.7% of those in Calgary responded “mostly true or strongly true” to the spirituality-based statement. Among those who responded “somewhat true and false,” 25% resided in Halifax, 25.7% in Toronto, and 17.5% in Calgary. Meanwhile, 11% of participants who resided in Halifax, 24.7% in Toronto, and 16.8% in Calgary responded “strongly false or mostly false” to the statement. A combination of the “strongly or mostly true” and “somewhat true and false” responses to the statement of culture-based spirituality in the three cities indicate that 89% of the Halifax sample, 83.2% of the Calgary sample, and 75.4 % of the

TABLE 2 Culture-Based Spirituality and City

City of residence	Strongly false or mostly false	Somewhat true and false	Mostly true or strongly true	Total	Total
Halifax (%)	11	25	64	300	100
Toronto (%)	24.7	25.7	49.7	300	100
Calgary (%)	16.8	17.5	65.7	297	100
Total (%)	17.5	22.7	59.8	897	100

Note. Racism, Violence, and Health (RVH) Project, 2006.

Toronto sample responded in this manner. This combined result suggests that the lives of African Canadians resident in Halifax are strongly influenced by culture-based spirituality, followed by Calgary, and Toronto has the least influence.

DISCUSSION

While investigating the impact of violence and racism on the health and well-being of African Canadians in Halifax, Toronto, and Calgary, the RVH project also examined the strong influence of culture-based spirituality on these community members. Based on the findings of the RVH project, the lives of African Canadian community members are strongly influenced by culture-based spirituality. Although people of African Canadian origin are most influenced by culture-based spirituality, the lives of those of African and Caribbean origin are also strongly influenced by spirituality. Regardless of origin or immigration status, spirituality and religion significantly influence the lives of African Canadians and other groups in Canada.

Differences were found in the results of the RVH project and Statistics Canada on the level of gender. While African Canadian men and women have a very strong spiritual based influence in their lives, Statistics Canada reveals that there is significant variation in the degree of religiosity among men and women in Canada. While the African Canadian men and women place the same level of importance on spirituality in their lives, Canadian women in general are more religious than Canadian men.

Furthermore, the findings revealed that the lives of African Canadians and all other Canadians are more influenced by spirituality and religion as they age. The level of spirituality increases with age and the younger regeneration in Canada has a lower level of spirituality and religiosity. Irrespective of origin or immigration status, age, gender, city of residence, income, and education, elderly Canadians are more spiritual and religious. This is consistent with Clark and Schellenberg's (2006), findings from data from Statistics Canada General Social Survey (Canadian Centre for Justice Statistics, 2001) and the Statistics Canada Ethnic Diversity Survey (2002) that although there is a degree of religion among all Canadians, it increases with age, and the level of religiosity is much higher among Canadian women than men.

PHASE TWO FINDINGS

Our data analysis of the focus groups and in-depth interviews identified the following key themes: (a) Pastors play a role in supporting and perpetuating the "salvation" and "preaching freedom" message which is rooted in the legacy of slavery; (b) Regarding EOL, pastors see their role as supportive

and “being present” for patients and their families; (c) Pastors noted the difference in the EOL experience between those with faith (peaceful death) versus those without faith (difficult uneasy death); (d) spirituality plays a significant role for both caregivers and the terminally ill patient; (e) Nonchurch members did not seem to receive the same level of support as church members; multiple expressions of spirituality bring comfort; and (f) family caregivers are feeling stressed and overburdened.

Pastors Play a Role in Supporting and Perpetuating the “Salvation” and “Preaching Freedom” Message Which is Rooted in the Legacy of Slavery

If death is impending, they can learn to look at that as a pathway to something bigger and better.

Dating back to the legacy of slavery, the role of spirituality has been to preach a message of freedom and salvation. Whether in this life or the next, the hope for a better tomorrow has been foundational to the Black experience. Participants in this study reinforce those ideas, and at the EOL that salvation is envisioned as the next step on the journey. Dying is seen as going to a better place.

Spirituality for me is . . . I was there when she was diagnosed and they said she only had about six months. But because of my belief in Jesus I knew that she was going to go to a better place instead of sitting here on this earth in pain. And that gave me peace because I knew she was going to go to a better place.

As we found in our two previous studies, there is also a sense of fatalism, or a resignation to their fate, for some when they get to the stage of requiring palliative care. In one of the focus groups a participant said:

As for myself, I've been through everything just about, and I know where my brother has gone now. I know he went to see my mother, and my sisters and brothers. Like myself, I'm ready any time the Lord is ready to take me because of what I've been through, and I think I'm here on borrowed time now, so this is the way I feel about it. (Other participants: “Amen. Bless you.”)

That feeling of being on borrowed time was echoed and affirmed by other participants. Some participants said they feel a sense of peace and reconciliation at the time of death, a message that permeates the findings of this study.

Pastors See Their Role as Supportive and “Being Present” for Patients and Their Families at the End of Life

The pastors in our study talked about their role as one that brings peace and serenity for the person being cared for, and the caregiver. They helped bring a message of hope during the transition from life to death, and acceptance of the EOL journey. Whether the decedent attended church or not, spirituality and the presence of the pastor was significant. Their presence helped ease the pain and the sense of loss. All of the pastors and deacons we interviewed agreed that just being present and available for all involved was the most important contribution they made during the EOL journey.

Spending time with them. I'm a firm believer that the power of presence is a very necessary thing. It's not always what you say.

Well, typically my role is simply . . . well, it's not simple, but it's straightforward in that it's not only the person who is ill that requires care, but also the family and caregivers. So what I seek to do is be present among them. I visit them frequently, or regularly I should say, and provide spiritual comfort to them in the sense of reading scripture and having prayers and giving words of encouragement, and trying to ease the transition for them as they face death . . .

One of the Pastors talked about a vision of having a more holistic palliative care service, with spiritual leaders as an integral part of the team. He suggested that this should be expected when the focus is holistic care.

. . . I used to hear them say—at some nursing homes where I've been that we believe in holistic care but wouldn't do anything about the spiritual side of it. Man [sic] is body, soul, and spirit. We're not just a body that needs to be taken care of in a nursing home. We're a spiritual being . . .

Another said:

Church leaders need to be part of the support team that helps families and individuals to know and feel this is more than just a Pastor's spiritual duty, it's a caring community and church leaders are front-line support systems along with the Pastor.

Pastors also provide spiritual guidance, teaching, support, and assistance to the decedent, caregivers, and family members at the EOL. Some pastors envision this role in a more holistic way. If they are engaged and involved in the family's life at joyous life transitions, their presence and involvement at the difficult times is better integrated. For example, one pastor said:

When I become Pastor, I will collect all the information on birthdays and anniversaries, and if your birthday is coming, Pastor will be there for a visit. And if there is a special event—a graduation, whatever—Pastor will be there. What that gives me is a good relationship with my members and adherents so when something happens they're usually quick to call me because they know that we have a good relationship. If the member or adherent has a terminal illness, I will usually respond very quickly and go to see them wherever they are—at home or at the hospital—and try to assess where they are at. The beauty of God's word is that we have scriptures for pretty much every type of situation. If they're nervous, you want to bring them a sense of calm. Jesus always promised to be with us. A lot of people feel that when they are in a terminal situation that it either is a judgment from God or they are being forsaken or abandoned, so the Minister wants to assure the person that this is a natural part of our existence, and sadly sometimes it means that we are not going to regain our health. But we can look forward to other blessings. Give them the opportunity to know the only true God because he gives eternal life. The terminal illness is a temporary experience.

Focus group participants acknowledged the significance of Pastors at the critical stage of the journey.

Church is very important. I thank God for our pastors, especially my Senior Pastor. It's been some rough weeks and months, but every Sunday God gives the Pastor a word that I need to hear. And I thank God for church down below the hills with the pastors that we have.

The pastor would call me to get updates because he was a very busy man. And if I was down I would give him an update on how she was doing, and he would probably call her up and pray on the phone with her. And the next Pastor down, our Senior Pastor, he would do the same thing. They would always check with someone to see how she was doing. They played a big part.

Spirituality plays a significant role for both caregivers and the terminally ill patient: “. . . it's what was keeping me from losing it.”

Focus group participants and pastoral leaders all identified the significant role that spirituality played in their EOL care for a loved one. For many caregivers, their spirituality, belief in God, and their faith helped them to cope with the difficult journey of being with a loved one at the end of their lives. Some wondered how they would have coped if they were not believers. Spirituality is significant for the decedent and their caregivers, even if they are not members of an organized church. For those who belong to a church, there is a strong connection to church family and community, which promotes a sense of belonging, fellowship, and security. However,

nonchurch members did not receive as much support from the church, which we explore more below.

Spirituality is so important at the end of life . . . I don't know what people do at the end of life who have no spirituality. I don't even know how they cope because that wouldn't even make sense for me. I thank God I got something to believe. If you have nothing to believe in, it's a sad day.

I really think it did play a role. Just because knowing Dad was such a spiritual person, I really relied upon his faith and trying to honour him in the process. It was so amazing because we just had Dad at home. It was in the bedroom. For light we just had a lamp. We had gospel music playing the whole time. For me that was very soothing. It's very strange, but I found it very therapeutic. It was almost like healing. That was when I did break down, when I would try to join the tape and start singing or I would take the hymn book and start singing. And when he come in to sing with me, I'd lose it. It took over the house. We were just singing songs and playing hymns and letting the music play and it was very soothing to bring a peace to us.

As I said, basically I found the main role that I found is it [spirituality] offered a sense of peace to Dad himself. I noticed that he was a bit anxious at times. For some reason, it's very strange, but the last day [local radio station] 93.9 played gospel and sermons the whole time non-stop, no break. And just to see Dad at ease listening to it was helpful. It seemed to relax everybody else around. And for me I would say it's what was keeping me from losing it.

I would say the Serenity Prayer was what was the key that provided me with strength throughout the whole experience at the time of the accident, taking care of him while he was there and then after he passed, every day.

These findings are consistent with those from our earlier study, where "spirituality was highlighted as being an important dimension of EOL care for decedents, caregivers, their family, and the community (Maddalena et al., 2010). However, there was an incredible sense of relief when a dying family member experienced deathbed conversions to spirituality.

Yes, I think it did because the way he was going around, and well, we knew him as a real tough guy. When he realized what he was going through and the only help he could get was through the Lord, and he was going to a better place where peace and quiet and no troubles to go through, no soreness, no sickness to go through . . . so I think he was more at peace with that knowing that.

For my stepsister, when we found out that she was dying that day, we were driving back home and she started to cry. And I said, "You can't cry because I can't drive, so wait 'til we get to your house and then we'll both have a good cry." So when we went home, we sat down and she looked at me and said, "Why? You've been with me all these years and now look what happened." I said, "The only thing you need now in your life is Jesus Christ." And she said, "I know." And two days later, she called and told me she gave her heart to the Lord. That lifted my spirits. I knew then she was ready to go.

That sense of peace and serenity in knowing that one's loved one found salvation prior to death emerged repeatedly in the data.

Nonchurch Members Did Not Seem to Receive the Same Level of Support as Church Members

There is such a sense of relief when a dying relative makes a deathbed conversion that it begs the question about the type and level of support available to nonchurch members. We also have concerns about the pressure that caregivers and pastors might put on the palliative care patient if they are nonchurch members. The lack of support for nonchurch members who are dying is equivalent to lack of support for the caregivers as well.

... well I have two different scenarios. One was with my grandmother who was a woman of God and was in the church, and with my mother who didn't give her heart to the Lord until she was on her deathbed. There was a difference in that. For my grandmother there was so much support from the members and the Pastor. For my mother I found it didn't really come until after she gave her heart to the Lord. It doesn't mean that nobody came or anything like that, but she didn't have as much support as my grandmother had. I thought about that a lot.

In addition to the levels of support being different for those inside or outside the church, our participants also noted that the lived experience at EOL differs also.

There Is a Difference in the End of Life Experience Between Those With Faith Versus Those Without Faith

Some participants noted that those with faith had a more peaceful dying experience.

A pastor shared the uncertainty that is often present when a loved one has not made a public profession of faith, and cautions that we are not to judge.

We're taught as ministers of the gospel not to preach anybody into Heaven or Hell. I mean as far as trying to determine what their eternal destination is. Only God knows that. What we have are the promises that are made in the Word that if we believe, this is what happens. If we don't believe, this is what happens. But for families when they are unsure as to what their loved one believed, no confession of faith has ever been made outwardly, we just have to be careful in not rushing to judgment as to what their eternal destination is.

However, despite such caution, many of our family caregivers talked about their loved one experiencing a more peaceful death once there was an acceptance.

. . . knowing that my mother had accepted the Lord before she got too ill, but before that I was beginning to wonder. I said, "Lord, would you please speak to her in a way that she would be able to deal with this and be able to deal with that, and that we would be able to deal with one another?" And when she accepted the Lord as her personal Savior it made it a lot easier.

This view was shared by others.

It was like she was at peace. She didn't complain, not one day, and she wanted someone to read the Bible to her every day when she was coherent enough to tell them that and they still read it even after she couldn't speak anymore. I believe she was at peace and she knew what was coming, and she was ready.

As one of the pastors noted "[p]art of the reality of death is that death is always hard . . .," and the participants in this study all shared the view that spirituality in its many forms helped to make the transition easier for everyone involved.

Multiple Expressions of Spirituality Bring Comfort . . . Music, Prayers, "Being Present," Reading the Bible

The expressions of spirituality ranged from discussions about God, to prayers, singing, Bible reading, and the simple presence of a Pastor, spiritual leader, or friend. As previously noted, those who were active church members tended to have more active expressions of spirituality. For example:

With Mom it was because the Deacon and all of them would come by and they would have a prayer and talk and discussions for about 15, 20 minutes. Several of them came by. The Ladies Auxiliary of the church

came by one afternoon. It went on like that. It was really a relief. And she was very glad they would come by and there were days when she wasn't feeling up to it and I would say when the phone would ring, I was kind of nervous because she was this kind of person whose home was always open. So one day I said, "I don't think she's up to it." She was going down all the time. And she had a bad night, and all of a sudden she said, "Hand that phone here. I run this house, and they'll come 'til my eyes are closed." So I said, "Listen, open it to everybody regardless of how she felt." And made sure—oh Lord, Father help us—I used to say, "Father help us, don't forget the teapot."

One participant shared how her brother found humor in his talks with the Lord and that helped him through his difficult transition while in hospital.

With my brother, at night he would be talking with the Lord and he would say the Lord was down and telling him jokes and laughing and going on. Because the people that was in the bed next to him said, "Your brother was laughing all night, and he was telling us that he was talking to the Lord, and the Lord was cheering him up, and getting him ready to go into His arms."

The presence of the pastor also appeared to be significant for the majority of participants. One pastor noted,

I've had people look at me and say, I'm so glad you came today. We didn't do anything unusual but just be there, and talk with them when they want to talk, and share with them that way. . . . Every situation is different because people are different. It's "the power of presence"—I find that's more important now than it ever was.

As evidenced in these stories, spirituality is expressed in multiple forms to bring support, comfort, and care to an often overburdened family system at the EOL.

Spirituality Guides Family Caregivers Who Are Feeling Stressed and Overburdened

Despite the presence of spirituality in the lives of these family caregivers, most are feeling stressed, sometimes overwhelmed and burdened by the responsibility of providing care for a family member at the EOL, often without adequate support. Our Community Researcher stated ". . . the biggest area of concern for me is the lack of bereavement support or counseling our Black communities seems to access during this period in their lives." Many participants shared stories of being alone and shocked, as most did not even

know they were in the midst of “their last days.” However, they all provided loving care until the very end, and most felt they were able to do so because of their own spirituality. As one person said:

[W]hen you're caring for someone that you really love and you know that it's the end of their time it's very emotional, a little stressful sometimes, but you know that you're there to help them in any way that you can.

Others had similar painful memories, along with a sense of frustration at not being able to offer much to change the difficult situation.

Given the level of distress, the lack of access to palliative care services and supports from the health care system it is not surprising that focus group participants did not have access to postbereavement care services. The pain and emotion often turns into unresolved grief. Some of the pastors who were interviewed talked about this issue of unresolved grief and the legacy of avoidance.

It is a very hard time for families and most of our churches do very well in providing meals and supporting the family that way. We need more capacity to be comfortable with negative feelings. We come out of a history of pain and we don't want to deal with pain a lot. But caring for a sick loved one is a very painful process so we must not hesitate to use all the systems available to us in the church, in the community, from hospital, and see that we can approach the end moment and the continuation of life after as strong as possible.

DISCUSSION

While Canadian women in general are more religious and/or spiritual than men, the RVH data reveal a picture of both African Canadian women and men having a strong cultural based spiritual influence. Although a small proportion of African Canadians do not report having a strong culture-based spiritual influence in their lives, this does not mean that they are not spiritual or that spirituality has no influence in their lives. This may mean that even though they engage in spiritual and/or religious activities, they may not necessarily view it as having the strongest influence on them. In addition, as Bernard (1999) and Este & Bernard (2006) assert, one can be spiritual without necessarily being involved in religious activities or organized religion. Spirituality and religion therefore play an important role in the lives of African Canadians and all other Canadians irrespective of their origin/immigration status, area of residence, age, gender, level of education, and income. Canadians are involved in both private and public religious and spiritual practices. Hence, spirituality and religion play a central role in the

lives of African Canadians as it may serve as a coping mechanism for dealing with violence, racism, discrimination, health problems, and other stressors in their lives, including EOL care by family caregivers.

Facing the death of a loved one is a major life event which is typically very stressful. For many Canadians of African descent, the church and leading a spiritual life play an important role in coping with stress and major life events, including terminal illness and EOL.

In this current research, we identified a number of prevalent themes from our interviews with pastors and family caregivers. Pastors as spiritual leaders in communities provide support and comfort care at EOL for individuals with terminal illness and their families. The legacy of slavery and preaching freedom theology continues to be a part of the lives of people of African descent.

As was demonstrated in the literature, living a spiritually rich life provides people with a foundation upon which to cope with the stressful events in their lives, such as terminal illness (Banerjee & Pyles, 2004; Beagan, Etowa & Bernard, 2012; Este & Bernard, 2006; Mattis, 2002). Our current research found that those that self-described as “spiritual” tended to weather the storm of terminal illness and EOL better than those who did not live a spiritually rich life. Pastors noted the difference in the EOL experience between those with faith versus those without faith where those with faith experienced a more peaceful death compared to those without faith whose EOL journey was more difficult and uneasy.

As was found in our previous two studies examining EOL in Nova Scotia’s Black community there is a general lack of knowledge and awareness of available palliative and supportive care services. This is due in part to the family-centered care that is provided in African Nova Scotian homes and an avoidance of the health care system. In addition, there is a lack of knowledge among health care providers regarding the significance of spirituality for this cultural group.

Strengths

A major strength of this study is that the research opened an avenue for the voices of African Nova Scotians to be heard, whereas they are normally silenced or invisible in discussions about health and EOL care. Secondly, the use of secondary data analysis of data from a previous study helps to contextualize the findings from the qualitative study. Finally, and as noted above, this is the third study this research team has conducted that focused on the EOL experience of African Canadians. In the first two studies spirituality was highlighted as an important dimension of the EOL experience of African Canadians. This current study was an opportunity for the team to examine in greater depth the importance of spirituality at EOL.

Limitations

The age range of participants in this study was 35 to 72 and did not represent or include the lived experiences of individuals between the ages of 18 and 30. The participant profile did not state whether or not all 14 participants were members of a religious institution. Moreover, the study did not include participants' definitions or perceptions of spirituality which may have shed more light on how individual beliefs, values, attitudes, and practices associated with being a spiritual person may shape participants' ability to cope with EOL and influence the level of social support they receive from the church and other community members.

While the study indicated different levels of experiences and support by individuals who had publicly expressed their faith and those who had not, the study did not further explore the difficulties faced by individuals who consider themselves spiritual but may not have publicly expressed their faith or did not belong to a church. The study did not use individual interviews to explore the extent to which spirituality impacts the level of social support that caretakers and family members who are terminally ill receive from community members before and after the EOL. These are areas for further study of these issues that may impact the role of spirituality at the EOL.

Implications for Social Work Practice

The role of spirituality at the EOL in Nova Scotia's Black community was explored in this article. Based on the results of the current study and secondary analysis of findings from the RVH Study (2002–2008), it appears that spirituality is significant for both caregivers and decedents at the EOL. Furthermore, this finding holds true whether the decedent is affiliated with a church or not. This is consistent with findings from other studies that explored the influence of spirituality, particularly on health (Breitbart et al., 2004; Knight & von Gulten, 2004; Pulchalski, 2001; Roberts et al., 1997). Clearly, the significance of spirituality at the EOL is one that requires further attention by the health care system. The place of spirituality in social work has gained prominence and prevalence in recent years (Coholic, 2002; Este & Bernard, 2006), and this is likely most visible in palliative care programs. In most health care settings, social workers are an integral part of palliative care teams. Critical social work theories help to prepare social workers for practice with diverse communities. It is particularly important that palliative care intervention programs be culturally relevant and culturally appropriate. Participants in this study, both pastors and family caregivers, have highlighted the significance of spirituality at the EOL for African Nova Scotians. Our findings suggest that attending to the spiritual well-being of those with terminal illness and their families can be an important dimension of holistic EOL care. Therefore, it is essential that practitioners understand

and accommodate this in their care plans. Hodge and Williams (2002) suggest specific questions regarding spirituality be asked as part of the assessment process. These questions focus on the following topics: spiritual beliefs and rituals, faith community, and God and transpersonal encounters. Questions about these experiences might be very useful for social workers who are working with African Nova Scotians at the EOL and in planning hospital or home-based palliative care supports.

On a macro level, social workers can be helpful in providing information to their team members about the role of spirituality in the lives of African Nova Scotians, and to determine how best to include spiritual leaders as a part of the palliative care team. Social workers could also consider ways they can help to bring greater awareness to the African Nova Scotian community about the range of services provided by palliative care or home care programs and how they can be accessed.

Similar to findings of other studies, spirituality is a source of strength, and a powerful coping mechanism (Beagan, Etowa, & Bernard, 2012; Este & Bernard, 2006; Mattis, 2002), and this holds true during the last stage of life for many African Nova Scotians. It can be a key component of the palliative care intervention plan to help African Nova Scotians transition through the various stages of illness from diagnosis to EOL and bereavement care for family members. Therefore, it is imperative that social workers and other palliative care practitioners receive training to fully understand how best to integrate spiritual leaders as part of care planning to meet the needs of African Canadian communities.

Further research is warranted to more fully explore the role of spirituality at the EOL for African Canadians and other marginalized groups. It would be especially useful to engage in action research to develop and evaluate culturally specific palliative care policy and programs.

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