

Cancer Care Experiences and the Use of Complementary and Alternative Medicine at End of Life in Nova Scotia's Black Communities

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Abstract

Purpose—This qualitative study examines the meanings that African Canadians living in Nova Scotia, Canada, ascribe to their experiences with cancer, family caregiving, and their use of complementary and alternative medicine (CAM) at end of life.

Design—Case study methodology using in-depth interviews were used to examine the experiences of caregivers of decedents who died from cancer in three families.

Findings—For many African Canadians end of life is characterized by care provided by family and friends in the home setting, community involvement, a focus on spirituality, and an avoidance of institutionalized health services. Caregivers and their families experience multiple challenges (and multiple demands). There is evidence to suggest that the use of CAM and home remedies at end of life are common.

Discussion—The delivery of palliative care to African Canadian families should consider and support their preference to provide end-of-life care in the home setting.

Keywords

African Canadians; end of life; complementary and alternative medicine

Qualitative case study methodology was used to explore the experiences and recollections of primary caregivers and secondary caregivers (e.g., other family members, neighbors, clergy,

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etc.) of decedents who died from cancer in three African Canadian families in Nova Scotia, Canada.¹ This research also explored whether participants used complementary and alternative medicine (CAM) and home remedies to ameliorate symptoms at end of life. Specifically, the objective of this inquiry was to examine the meanings that African Canadians ascribe to their cancer and end-of-life experiences. We also examine the use of home remedies and complementary and alternative healing practices at end of life.

This study was conducted in Nova Scotia, a small maritime province located on the eastern coast of Canada (population: 944,765; Nova Scotia Department of Finance, 2006). There are 19,670 people of African descent living in Nova Scotia, representing approximately 2% of the province's population. African Canadians account for more than half (52%) of Nova Scotia's visible minorities (Statistics Canada, 2003). Halifax, the provincial capital, has the highest proportion of Canadian-born Black people among major urban areas in Canada (Statistics Canada, 2003).

African Canadians living in Nova Scotia were some of the province's earliest settlers (not counting Aboriginal peoples), and much of their history has been characterized by racism, marginalization, and exclusion from the benefits of society. Although slavery was never formally instituted by statute in Nova Scotia, there is evidence of commercial trading of slaves in the province in the mid-1700s. The long-term influence of slavery, harsh treatment, and social and economic exclusion on the early Black settlers in Nova Scotia cannot be underestimated. Years of poor living conditions, racism, hostile treatment, and a widespread lack of acceptance and integration into Nova Scotia society has led to the creation of a Black community that has been, and continues to be, oppressed (Clairmont & Magill, 1987). The social and economic conditions experienced by many Black people in Nova Scotia have directly or indirectly influenced their health status.

Literature Review

Although only a limited amount of research has been conducted thus far on the health status of African Canadians, extensive research conducted in the United States has shown that African Americans have reduced access to health services and poorer health status than the general population (Friedman, 2002; Karlson & Nazroo, 2002; Manton, Patrick, & Johnson, 1987; Nazroo, 2003; Physicians for Human Rights, 2003). The available data for African Canadians suggest similar patterns of poor health and reduced service availability (Cancer Care Nova Scotia, 2001; Enang, 2002; Maddalena, 2005; Thomas Bernard, 2002; Thomas Bernard & Bernard, 2000). Moreover, it has been documented that racial and ethnic minority patients have reduced access to palliative care services and pain and symptom management (Krakauer, Crenner, & Fox, 2002; Siriwardena & Clark, 2004).

In Nova Scotia, there are two general populations of people of African descent: those descendents of the Black Loyalists, Refugee Blacks, Trelawney Maroons, and other lesser migrations that came to the province in the period 1780 to 1815 (often referred to as

¹In this article, the terms *African Canadian* and *Black people* are used interchangeably and refer to people of African descent. Local nomenclature further identifies *African Nova Scotians* as people of African descent who settled in Nova Scotia prior to 1815.

“African Nova Scotians”) and those immigrants that have arrived more recently from African or Caribbean countries. Although this may suggest, in one sense, a unified cultural community, there is considerable diversity among African Canadians living in Nova Scotia in terms of, for example, age, gender, income, education, ability status, employment status, place of residence, health status, religious affiliation, sexual orientation, and country of origin. There is, however, for many African Canadians, a sense of shared cultural identity that influences individual and family experiences of illness, suffering, pain, and dying.

In the United States, Reese, Ahern, Nair, O’Faire, and Warren (1999) observe that a similar diversity exists among African Americans:

Within this diversity, however, a cultural unity may be detected that traditionally has characterized many African American families, and during the great stress of terminal illness, patients who normally do not adhere to ethnic culture may resort to traditional modes of behaviour. (p. 550)

Crawley et al. (2000) also note that among African Americans there is a rich religious tradition and that these spiritual beliefs and practices influence understandings of illness and death. For example, death may be viewed as a “welcome friend” and that individuals who have died are said to have “gone home” (Crawley et al., 2000; Dula, 1994b). It may be useful at this point to summarize some of the traditional beliefs around death and dying among African Americans. Reese et al. (1999) summarize this well. They state,

Traditionally, African Americans believe in the omnipotence of God. Illness and death are God’s will and are not necessarily affected by treatment. At the same time, God is benevolent and has miraculous powers—God is able to cause recovery or turn into good ends whatever may occur. Another traditional belief is the belief in a better life after death, without sickness, disease, poverty, or hunger, a life in which victims of injustices will be compensated. Thus there is little apprehension at the prospect of dying; rather a sense of joy may be detected. When a death is expected, the dying person is surrounded by the community, which offers comfort and support. (p. 551)

It is widely acknowledged, for example, that cultural beliefs and social mores influence how individuals make sense of various life experiences including illness, suffering, pain, and dying (Kagawa-Singer & Blackhall, 2001). Although the available research clearly describes the African American experience, there is, however, no research available examining the experiences of palliative care and end-of-life experiences among African Canadians. Available evidence, however, suggests similar issues arise in African Canadians’ experience with access to health care and end-of-life care. Reese et al. (1999) argue that it is important for health workers (and we would argue policy makers) to be informed about traditional beliefs around illness and death, while at the same time avoiding stereotypes and “unquestioning assumptions” (Reese et al., 1999).

There are also cultural differences regarding the beliefs and practices of people from African and Caribbean cultures regarding palliative and end-of-life care (Spence, Merriman, & Binagwaho, 2004). Local culture, economics, and history shape these beliefs, and although

similar in some ways to the experiences of African Americans or African Canadians, there is little comparative research available.

As stated above, within the Black community in Nova Scotia, there are several distinct cultural communities, those that came to Nova Scotia prior to 1815, referred to as “African Nova Scotians,” and more recently, immigrant people of African descent, for example, those from African and Caribbean countries. Although there may be some similarities in cultural beliefs regarding death, illness, palliative care, cancer, spiritual beliefs and practices, and advanced directives, there is little documentation regarding these beliefs and practices among these three cultural communities in Nova Scotia. This research begins to document these similarities and differences and explores how they influence cancer care and end-of-life care.

Cultural Barriers to Accessing Palliative Care

The literature examining end-of-life care issues in the African American community documents a heterogeneity of needs and a wide range of barriers to accessing culturally appropriate palliative, hospice, and end-of-life care. In a study conducted by Reese et al. (1999), they describe two prominent cultural barriers African Americans experience accessing palliative care: differences in values regarding medical care and differences in spiritual beliefs. Reese et al., in their study of 127 African Americans and European Americans, found that African Americans tended to reject the view of planning for (and even discussing) death. Rather, participants opted instead for life sustaining treatments, such as chemotherapy, resuscitation, life support, and artificial nutrition as opposed to palliative care. Participants stated that, rather than have strangers provide care for a terminally ill individual, it was more culturally appropriate for family and church members to provide care at end of life.

The second cultural barrier to accessing palliative care described by Reese et al. (1999) was the difference in spiritual beliefs that lead many African Americans to opt for prayer rather than accept terminality of disease and that it is God that determines whether someone lives or dies. Although there is a belief in the omnipotence of God, there is still a desire for receiving life-saving treatments, because these too are seen to be interventions from God. Cultural barriers to accessing palliative care are well documented in the literature (Bourjolly, 1998; Dula, 1994b; Mouton, 2000; Nobles, 1974; Robertson, 1985).

Institutional Barriers to Accessing Palliative Care

Reese et al. (1999) in their study describe a lack of knowledge of services, economic factors, lack of trust by African Americans in the health care system, and lack of diversity of health care staff as being institutional barriers to African Americans accessing culturally appropriate palliative care. Regarding lack of knowledge, their study found that even among pastor participants there was limited knowledge of palliative care services. This is significant given the importance of the religious community’s role in providing support and guidance at end of life. Their study also found that economic factors served as barriers to accessing palliative care. Although this study was American—and private health insurance is an issue

for many—there are still economic barriers in the Canadian context, including, for example, costs associated with transportation, lost days of work, uninsured medicines and treatments, and child care.

Lack of trust by African Americans in the health care system was a recurring theme that was documented in several studies of African Americans (Crawley, 2002; Dula, 1994a; Jenkins, Krakauer et al., 2002; Lapelle, Zapka, & Kurent, 2005; Reese et al., 1999). The concern for many Black people is that the health care system would not offer life-saving treatments or that health professionals would somehow seek to hasten their death. This fear of racism in the delivery of health care is well documented in the literature and serves as a significant barrier to African Americans seeking palliative and other health care services (Burrs, 1995; Caralis, Davis, Wright, & Marcial, 1993; Crawley et al., 2000; Dula, 1994a, 1994b). Crawley et al. (2000) state,

The legacy of slavery, abuses in medical experimentation, economic injustices, racial-profiling practices, and the disproportionate numbers of incarcerations, to name a few, reflect social and ethical misconduct that has led to a general loss of credibility of many institutions, including the health care system. Death has often been associated with these societal patterns. (p. 2518)

Furthermore, socioeconomic and environmental inequities between African Americans and non-Black people have been correlated with higher rates of diseases such as cancer, cardiovascular disease, and AIDS, among others (Crawley et al., 2000).

Fear of “medical racism” (historical support and justification by the medical profession to condone the use of Black people as slaves) by physicians is also cited by Krakauer et al. (2002) as a significant barrier to accessing palliative care. Krakauer et al. (2002) state,

The history of American medicine includes tortuous exploitation, deception, withholding of needed treatment, experimentation without consent, coerced treatment, and stigmatization, perpetuated by healthcare institutions and physicians upon African American and other minority patients. Given this history of medical racism, and given widespread inequalities in access to health care today, mistrust is not surprising. (p. 186)

In this regard, disparities in access to culturally appropriate palliative and end-of-life care based on cultural background tend to reflect disparities in access to other types of health and social services (Krakauer et al., 2002).

Complementary and Alternative Medicine and Home Remedies

The use of CAM and home remedies (also known as folk remedies) is common in many cultures and originates from a complex relationship between health-related beliefs and social beliefs and practices (Pachter, 1994). Folk or home remedies are usually made from locally available herbs, food products, or household items (Smitherman, Janisse, & Mathur, 2005). Historically, community reliance on home remedies or folk medicine was often related to a lack of access to, or knowledge of, modern health care services resulting from shortages of health professionals; socioeconomic, language, or cultural barriers; or mistrust of

conventional medicine (Smitherman et al., 2005). For many, folk medicine is the preferred choice because of a belief that home remedies are more effective than conventional medicine, and this may be due, in part, to handing down healing beliefs and traditions from one generation to another (Smitherman et al., 2005).

It is well documented that, in the past 10 years, there has been a significant increase in the general use of CAM, and there has also been an increase in the use of CAM in the treatment of cancer across most segments of society (Barrett, 2003; Cuellar, Aycock, Cahill, & Ford, 2003; Ernst & Cassileth, 1997; Shumay, Maskarinec, Gotay, Heiby, & Kakai, 2002; Tataryn, 2002). A systematic review conducted by Ernst and Cassileth (1997) concluded that “the use of CAM in cancer is common and widespread” (p. 781).

There is evidence to suggest that, among African Americans, both CAM and home remedies are used, either because they are believed to be effective or because they are seen as an alternative to conventional medical treatments (Dula, 1994b; Pachter, 1994; Reese et al., 1999; Smitherman et al., 2005). Although it is generally accepted that CAM and folk remedies are part of African Canadian culture, this phenomenon has not been documented in the literature.

Method

In this research project, we used a qualitative case study methodology to explore and document the experiences and recollections of primary caregivers and significant others (family and community members involved in their care) of decedents who died from cancer in three African Canadian families in Nova Scotia, Canada.

We adopted the definition proposed by Orum, Feagin, and Sjoberg (1991), wherein they define a case study as “an in-depth, multifaceted investigation, using qualitative research methods of a single social phenomenon” (p. 2). In this regard, the decedents in three African Canadian families are the subject of interest, and the particular social phenomenon of interest is the cancer care experiences of the decedents and their caregivers.

The research team (with the exception of Maddalena) is African Canadian. The Research Ethics Board of the Capital District Health Authority, Halifax, Nova Scotia, approved this research study. The research was conducted in 2005–2006.

Participant Selection

Purposeful sampling was used to select research participants. The decedents—all African Canadian—were identified based on their membership in one of the following categories: geographically located in an urban setting, geographically located in a rural setting, and a recent immigrant, specifically, within 5 years of immigrating to Canada.

Inclusion criteria specified that the individual must be African Canadian and either a primary caregiver for someone who has died from cancer within the last 3 years (and no sooner than 6 months) or someone identified by the primary caregiver as being someone who was involved in the care of the decedent (secondary caregiver). Primary caregivers were asked to identify other individuals who were involved in the care of their loved one (referred to as

“secondary caregivers), including, for example, family members, neighbors, health professionals (including alternative or complementary healers, if applicable) and religious or spiritual leaders from the decedent’s faith community. Originally, within the immigrant category, we wanted to include one immigrant family from the Caribbean and one from an African country. We were unable to identify a family who met the inclusion criteria from an African country. Thus, three cases studies were examined: one rural family (African Nova Scotian), one urban family (African Nova Scotian), and one immigrant family (Caribbean). For the three case studies, there were three primary caregivers and four secondary caregivers (members of their extended family and community) interviewed, for a total of seven participants.

The main source of data in this study was individual in-depth interviews with primary caregivers. Interviews were also conducted with secondary caregivers to further explore, and build a fuller picture, of the cancer experiences and end-of-life care of the decedent. This also facilitated triangulation of data within the case study. Two follow-up interviews were conducted to seek clarification on issues raised in the first interviews: one with a primary caregiver and one with a secondary caregiver. Interviews were audiotaped. Interviews were conducted by trained researchers from the Black community. Specifically, each interview explored the following areas:

1. Their cancer experience from the time of diagnosis to death and their experience with the conventional health care system, including their experience with the cancer care system
2. How they (the individual, the family, the community) dealt with end-of-life issues such as palliative care, care responsibilities, home care, spiritual care, and management of pain
3. Their use—and reasons for the use—of CAM and home remedies

The Black community in Nova Scotia is small and social networks are close; therefore, to protect the identity of the participants, demographic and other descriptive information of the participants are not provided. Suffice to say the caregivers in the urban and rural cases were younger women (age range = 25–35 years), and in the case of the immigrant family, the primary caregiver was male and the secondary caregiver was female (age range = 50–60 years).

Data Analysis

Interviews with the primary and secondary caregivers were transcribed verbatim. Transcripts were coded manually by four members of the research team for relevant theme areas and for unique or novel narratives. A 1-day research meeting of the researcher team was held to compare coding and engage in analysis of the data. Differences of opinion among researchers were discussed and resolved to ensure consistency of coding and interpretation. In situations where both the primary and secondary caregivers were interviewed, we compared accounts to triangulate data within each case study.

The researcher’s shared understanding of qualitative research is that it seeks to conceptualize the world and to communicate a story, a message, or an idea (Vidich & Lyman, 2000) and is

supported by epistemologies that suggest there are multiple realities and “truths” and these “truths” are socially constructed by the participant and the researcher’s social, political, cultural, and gender values (Schwandt, 2000).

As a research team, we also approached this study with the belief that storytelling is a powerful means of communicating the experiences of individuals and an integral feature of Black culture. Interviews focused on asking participants to “tell their story.” The story to be told in this research was constructed with the assistance of the shared experiences of the participants, that is, the primary caregivers and secondary caregivers and interpreted through the subjective lens of the researcher team.

Through our data collection, we engaged participants in a process of interactive dialogue wherein we explored ideas and experiences around the end-of-life experiences of decedents who died from cancer. Hence, the caregivers’ experiences were not isolated events, but rather they took place in a particular social, cultural, political, and historical context. Schwandt (2000) further clarifies this process and suggests that “there is an inevitable historical and socio-cultural dimension to this construction. We do not construct our interpretations in isolation but against a backdrop of shared understandings, practices, language and so forth” (p. 19). The shared understandings are defined by the history and culture of the Black community in Nova Scotia.

We used thematic analysis and discourse analysis to analyze our data (Coffey & Atkinson, 1996). In discourse analysis, the underlying assumption is that the use of language—the presence (or absence) of words, phrases, statements—is used to create and convey perceptions of reality, and this use of language (as text or narrative) can be subject to analysis (Fairclough, 1989). In this regard, we understand discourse analysis to be an *approach* to analysis and not a *method* and that it is concerned primarily with the way texts and narrative are constructed and situated in terms of their social, political, cultural, and historical context (Cheek, 2004). In this regard, we examined our data through a cultural “lens,” specifically we examined—and made sense of—the data through the shared historical and cultural experiences of the Black community.

We began our analysis by identifying prevalent themes arising from the interview data, and within each theme we explored how culture influenced their experiences with cancer, end of life, management of pain, coping mechanisms, and how they interacted with the health care system. We were particularly interested in how the family unit (decedent and caregivers) “traveled” on their collective journey through diagnosis, illness, management of symptoms (including the use of CAM and home remedies), interactions with the health system, death, and bereavement.

The research team’s knowledge of Nova Scotia’s Black community and Black culture played an important role in the analysis of the data. The researcher’s “insider” knowledge (Acker, 2001) of the Black community and Black culture facilitated analysis of the data by providing a cultural and historical context for Black people’s experiences living in Nova Scotia, for example, interactions with the health system and cultural norms related to pain and death that may not otherwise be known to those unfamiliar with the Black community.

Field notes did not play a significant role in our analysis, likely due to the fact that the interviews were conducted by a research assistant and not the investigators.

Findings

During the process of analysis, the research team identified four prevalent, recurring themes, including (a) roles and expectations of caregivers, (b) lack of knowledge of both the health system and the disease, (c) the importance of spirituality during their illness and death, and (d) complementary and alternative healing practices.

Roles and Expectations of Caregivers

One of the more striking themes that emerged during the interviews was the widely held view that among African Canadians there is an expectation that family members—typically, though not exclusively, women—will assume the primary caregiving role during chronic illness and at end of life in the home setting.

Because it's a known fact that us, as Black families, when our family members get sick, we do not put them in a nursing home. We take care of them.

Moreover, there was reluctance on the part of the caregiver as well as the decedent to use conventional institution-based palliative and supportive care. From the perspective of the decedent, the preference was for home care.

She didn't want to go to the hospital, she didn't want to be in a home, and she didn't want outside nurses or people coming in to do anything for her. We had certain family members that would come daily. Some of them were there every day, some come once or twice a week.

In each of the three case studies, participants described considerable hardships by taking on the caregiving role. In addition to the responsibility of caring for a loved one who has a terminal disease, adopting the caregiving role often means additional personal and financial responsibilities for individual caregivers and their families.

For example, in one of the case studies the caregiver, a single mother, left her job so that she could move home to care for her mother. By assuming the caregiver role family members often put their own life aspirations aside to care for a loved one out of a deep sense of commitment and responsibility.

I'm working, making good money, finally getting on my feet and doing what I had to do and I gave my notice at work and I said, my Mom is sick and I've got to go home. I quit. I gave everything away and I moved home with my daughter and that was it. I did it because she would have done it for me. She did everything under the sun for me when I was growing up.... I did what I felt was right.

The role of the caregiver is complex and in most instances individuals who assume the role often fulfill multiple roles within the family unit. In this regard, it was noteworthy that the decedents themselves—all women—were also serving in the role of caregiver up to the point of (and sometimes during) their own terminal illness.

She didn't want to be a burden to anybody or for us to know her suffering or pain because that was her thing ... I don't want to be a burden to anybody and I don't want to bother anybody ... because she was a caregiver and she held that role for many, many years.

The primary caregivers in the three case studies cared for their loved ones during their illness, while at the same time caring for their own family and meeting their own personal needs. In one of the case studies, the decedent who was advanced in age was caring for a young adopted child during her own illness. When the decedent became too ill to care for the child, the primary caregiver stepped in to care for the decedent, and also assumed responsibility for the adopted child. This sense of responsibility to care for family members was accepted as an unquestioned duty and in this manner seamless care was provided to the family unit.

Lack of Knowledge of the Health System and the Disease

Most of the caregivers in this study (primary and secondary) expressed a limited understanding of how to access necessary supports from the health and social service systems to assist them in providing care and accessing financial assistance for their loved one. There was one exception, and in that case the caregiver was a health professional and was comfortable navigating the health and social service system. It is interesting to note that even though the primary caregiver was a health professional, there was still a preference for family based, in-home care during the decedent's illness and a home death. Moreover, caregivers expressed the view that they often had a limited understanding of their loved one's disease. A wide range of reasons were cited, including denial of diagnosis, the decedent seeking to shelter the family member from the emotional pain and stress associated with a terminal diagnosis (again, still serving in the caregiving role while facing illness), a traditional reluctance to discuss the diagnosis of "cancer" and terminality of disease, and a lack of information and adequate follow-up from professional caregivers.

Participants also noted a lack of follow-up care available for caregivers, specifically bereavement care, following the death of loved ones. This was notable in all cases, but more so in the rural case study because of transportation issues and lack of service.

I've looked at going to support groups but I'm a single parent, so for me to go to a support group 90% of them are not in this town so I've got to travel and gas is ridiculously high ... then you have to pay for a baby sitter and there's a lot of stuff in the evenings, the kids have to get ready for school the next day so, you know, there's so many things compounding this.

Spirituality

In each of the case studies spirituality was highlighted as being an important dimension of end-of-life care for decedents, caregivers, their family, and the community.

So we read the Bible, we prayed, we sang Mom's favourite hymns and friends and neighbours came ... so we relied on each other and the Lord.

Personal and family prayer, prayer vigils, hymns, gospel music, Bible reading, involvement of the church community (including pastors) were all integral to the sense of well-being of the decedent during the terminal illness, particularly in the period immediately preceding death. In one of the case studies, the decedent, nearing end of life, wanted a full immersion baptism as a way to “clear her soul,” to prepare for going to be with God.

She wanted to be baptised. Even with all the surgeries she had and all the holes in her body that were not supposed to be wet. So she had them tape her up and when she was offered sprinkling she said no, she didn't want any sprinkling, she wanted a full baptism. She wanted to go in the water just like Jesus. She wanted to follow in the footsteps of Jesus even in her last days. It was a happy and a glorious day on that day that she was baptised.

One additional spiritual theme that was present in all the case studies was the expression of a kind of “fatalism,” that is, resignation to fate that accompanied their circumstances that was grounded in their belief in the omnipotence and benevolence of God. This was manifested in a stated belief that, despite the terminality of their disease and hope for treatment or cure, there was an acceptance that, “it's my time,” or “it's God's will.” This resignation to fate was often expressed as part of their refusal for further treatment or even medication to relieve pain and suffering. A caregiver describes how one of the decedents, when offered pain relief stated,

They came around with their little carts but [she said] “Nope, I've made peace with God.” At some point, towards the end, when she went into the hospital, she said she talked to God. Now, I'm not someone to say yes she did, or no she didn't, but she said she had a connection with some higher power and she said that God has forgiven me for all my sins and for all the wrong I've done and I'm at peace now and she closed her eyes and dozed off to sleep ... [she said], “I made peace with God and he has forgiven me and I'm at peace now.”

The decedents' expression of making peace with God was a common experience during final days as they neared death. Spirituality, prayer, and participation in the church community were also an important part of bereavement and healing for family members.

Complementary and Alternative Medicine

CAM and home remedies were used during the decedent's illness in each of the three case studies. Caregivers self-identified a variety of CAM and home remedies that were used by decedents including, for example, alcohol and marijuana (for pain management), Aloe Vera, Essiac, vitamins, and massage therapy. In each of the three case studies caregivers self-identified “prayer” as a CAM therapy. In one case, a friend of the family offered the person marijuana to ease the pain because she would not take her pain medications.

At first she said no that's not going to help me and it got to the point where she was like, I'll try anything ... and once she took a puff off this, it made her feel better, subsided whatever pain she was feeling and from then on she swore by it. She'd say, if you don't feel good, smoke a joint.

The most common reasons cited for using CAM and home remedies included relief from emotional and physical pain, improving appetite, and a general sense of wellness and offering hope of cure. Though not typically identified as CAM, there was also evidence of inappropriate use of medications, for example, using medication that had been prescribed for another family member and for a different purpose.

My dad had angina and had nitroglycerin, you put under the tongue, so when she would have the panic attacks, and she would use his nitroglycerin. To her it made her feel better so, you know, it didn't make anything worse, she felt better so even I said you really shouldn't do that, that's not your medication, nope, it helped and it works so she was taking it.

It is acknowledged that home remedies can also serve as a way to avoid seeking health care; a kind of denial. In one of the case studies this denial and refusal to seek conventional treatment and opt for home remedies instead was evident. In the following dialogue, the caregiver describes the advanced state of the decedent's cancer and her fear of conventional medicine:

She let it go for ... I think it was two years ... after a while it [breast lump] was big enough so that she could feel it. There was a discharge ... it was like a brownish color ... and then it was leaking out of her breast ... and after a while it started to hurt. Like at first she'd wear breast pads and stuff so it wouldn't leak out all over her clothes and stuff and then it started to hurt her so that's when she went for her mammogram. If it was us ... [she would say] "come on now you've got to go to the Doctor to see what's wrong" but for her she'd figure out a home remedy or she'd find something else unless it was really bad that she couldn't cope with it herself or figure out a way to treat it.

Discussion

As Canadian society becomes increasingly diverse, health services will need to be evaluated in terms of their ability to attend to the health needs of different cultural groups in a manner that is "culturally competent" (Maddalena, 2009, in press). In this regard cultural competence refers to

the process of actively developing and practicing appropriate, relevant, and sensitive strategies and skill in interacting with culturally different people. The capacity to respond to the needs of populations whose cultures are different from what might be called dominant or mainstream.

(Wells & Black, 2002, p. 278)

It is clear from the stories and concerns expressed by caregivers in this research (and based on the researcher's knowledge of Nova Scotia's Black community) that there is a preference for family-centered caregiving in the home setting at end of life. These findings are consistent with the American literature (Crawley et al., 2000; Reese et al., 1999). Data from this research support the view that within the Black community there is a tradition of family- and community-centered care of the terminally ill and a deliberate avoidance of institutional care.

There were examples of rural–urban differences in the caregiving experiences. The rural case study clearly identified issues related to transportation, access to health services, and amenities during their caregiving experience. These issues were often compounded by the decedents’ and the caregivers’ limited knowledge of their disease and the health care system. In this regard, policy makers need to be aware that not all members of our communities access—or have knowledge of—palliative care services. Thus, there is an opportunity to educate health professionals and policy makers regarding preferences for home-centered care for Black families and an opportunity to educate Black communities about services that are currently available to support home-based end-of-life care.

Preference for caring for loved ones at home may render many African Canadian families “invisible” to the palliative care network of services. Seeking input and participation from the Black community, by partnering with community leaders to ensure services are tailored to meet their unique circumstances, is a positive first step toward developing culturally competent care for this community.

It is also important to be aware of the multiple and compounding vulnerabilities associated with caregiving. Caregivers in this research described their multiple responsibilities and burdens, both personal and financial, in addition to the challenges of caring for their loved one who was dying. This was a consistent source of concern identified by caregivers in this research. Issues such as single parenthood, rural isolation, low income, limited knowledge of the health system, transportation issues, lack of comfort with navigating the health system, managing emotional and physical pain, in addition to the overwhelming issue of caring for a loved one with a terminal disease, compound the challenges associated with caregiving. Most of these issues are dealt with within the extended family and community.

Findings from this research suggest there are several areas worthy of further exploration regarding end-of-life care in the Black community, including, for example, understanding the role of spirituality in terminal illness, caregiver and family knowledge of the health and social service systems to support end-of-life care, cultural understandings of pain and suffering, and rural–urban differences in cancer experiences. There is also merit in further exploring the use of CAM and home remedies in Black communities.

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