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Awareness of Palliative Care and End-of-Life Options Among African Canadians in Nova Scotia

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Abstract

Purpose—To assess, using qualitative methods, the knowledge African Canadians living in Nova Scotia have regarding their options for palliative and end-of-life (EOL) care.

Design—This project engaged caregivers in a Black community in Nova Scotia, Canada, in an exploration of palliative and EOL care. A group of six caregivers who cared for someone who had died were recruited through purposive sampling. The caregivers met three times to (1) discuss their experiences, (2) receive a presentation from the palliative care service, and (3) discuss whether those services would be beneficial. This was followed by a community meeting to discuss the findings.

Findings—Knowledge of options for palliative care services is limited. Family centered care may be a reason why "system" is generally not aware of the EOL experiences of African Nova Scotians.

Discussion—Information about palliative care services is not filtering down to the community in a way that is meaningful to families. Families tend to self-select services that assist them in providing care in the home setting. There is a need to engage Black communities and palliative care services in developing culturally appropriate services.

Keywords

end-of-life care; transcultural health; qualitative research; African Canadians

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For many African Canadians living in Nova Scotia, palliative care services have historically been underutilized. Family centered care in the home setting at end of life is common and,

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indeed, preferred. As a result many caregivers have limited knowledge of the types of services that are available to them to support them in their caregiving role.

Participatory action research (PAR) and naturalistic inquiry were used to examine the knowledge African Canadians[1] have, and need, to evaluate their options for accessing palliative and end-of-life care. This research builds on the findings of a previous study (Maddalena, Bernard, Etowa, Davis-Murdoch, Smith, & Marsh-Jarvis, 2010) that examined the meanings African Canadians ascribe to health, their cancer experiences, their access to conventional cancer care, and their use of complementary and alternative medicines and home remedies at end of life.

Our first study documented patterns of care among African Canadians that emphasized the expectation that family members will assume the primary caregiving role during chronic illness and at end of life in the home setting and that most caregivers experience multiple caregiving demands. Paramount among the findings from our first study was that caregivers had limited knowledge of the support services available from the provincial (publicly funded) health and social service systems to enable them to care for their loved one in the home setting. It is this dimension of the family caregiver's experience—their knowledge of available palliative and end-of-life care services—that was the focus of the current project.

Background

This study was conducted in Nova Scotia, a small coastal province in eastern Canada (population: 944,765; Nova Scotia Department of Finance, 2006). African Canadians (population: 19,670) account for more than half (52%) of Nova Scotia's visible minorities and 2% of the province's population (Statistics Canada, 2003). Among major urban areas in Canada, Halifax Regional Municipality has the highest proportion of Canadian-born Black people (Statistics Canada, 2003).

There are two general populations of Black people in Nova Scotia: those descendent from early settlers (prior to 1815), including Black Loyalists, Refugee Blacks, and Trelawney Maroons; and more recent immigrants from Africa, the Caribbean, and other countries. Although there is considerable diversity among Black people living in Nova Scotia, many share a common cultural history. Historically, and in more recent times, African Canadians have been subjected to discrimination, injustice, exclusion, and institutionalized racism (Black Learners Advisory Committee, 1994a, 1994b, 1994c; Head & Clairmont, 1989). As a result, Black people often experience the physical and social ill effects of lifelong exposure to racism, and concomitant poor health and reduced access to health services (including palliative care) are common (Bernard, 2002; Bernard, 2005; Bernard & Wien, 2001; Black Learners Advisory Committee, 1994a, 1994b, 1994c; Cancer Care Nova Scotia, 2001; Enang, 2002; Etowa, Bernard, Clow, & Oyinsan, 2007; James, Este, Bernard, Benjamin, & Lloyd, 2010; Maddalena, 2005).

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[1]In 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.

Although there is a limited body of research on African Canadians and end-of-life care, lessons can be learned from the African American experience regarding access to and information about palliative care services. Previous research in the African American community documents the importance of information in terms of influencing decision making at end of life (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Rhodes, 2006; Taxis, 2006; Volandes et al., 2008). Born et al. (2004) examined end-of-life preferences and barriers to accessing hospice services among low-income African Americans and Latino/Hispanic Americans. Lack of awareness of hospice services and a lack of understanding of what constitutes "hospice services" were identified among focus group participants as being significant barriers to accessing services. A lack of understanding of hospice services was due in part to cultural traditions of the family assuming the caregiving role during terminal illness. Rhodes, Teno, and Welch (2006) examined whether African Americans were informed about hospice services. They examined demographic and disease factors to see if there was any particular correlation with knowledge of hospice services. Their results showed that 53.8% of participants were not informed about hospice services, and of those who were informed, the leading cause of death was cancer. They concluded that patients, regardless of their diagnosis should be informed about hospice services, and efforts should be made to increase information sharing in the African American community. Similarly, Carole Taxis in her 2006 study of African American attitudes and values regarding participation in hospice programs also found that a general lack of information regarding hospice services played a role in whether services were used by the Black community. Volandes et al. (2008) in their study comparing African Americans and Caucasians found that health literacy, and not race, was a more significant predictor of end-of-life preferences for care.

Preference for family- and community-centered care in the home setting, a general mistrust of health care providers, and a fear of racism suggest, however, that the provision of information alone may not be sufficient to overcome barriers to accessing care (Burrs, 1995; Crawley et al., 2000; Dula, 1994a, 1994b; Dupree, 2000; Etowa et al., 2007).

Purpose

This research project focused on answering the following research questions:

1. What are the prevalent understandings of African Canadians regarding their options for accessing palliative care and end-of-life care services?

2. What measures are lacking to support the "family and community" model of care that is prevalent in African Canadian communities?

3. What influence does knowledge of palliative and end-of-life care services have on the way services are used?

4. What kinds of policy changes are needed to improve access to equitable end-of-life care for African Canadians and their families?

Method

This research project used qualitative research methods, in particular, naturalistic inquiry and PAR as a means to engage a representative Black community in Nova Scotia in an exploration of issues related to information and accessing palliative and end-of-life care. Naturalistic inquiries are grounded in the ontological view that realities are multiple and socially constructed and dependent on context. It is through the process of conducting research that the researcher and the participant develop a shared understanding of the phenomenon of interest. Naturalistic inquiries are conducted in natural surroundings (the places people live and work) and analysis of data is inductive (Erlandson, Harris, Skipper, & Allen, 1993; Lincoln & Guba, 1985).

Participatory research adheres to the belief that ownership of the research project, analysis, and outcomes are shared between the researcher and participants. The principal objective of participatory research is for the researcher and participant to collaborate through the research process to bring about action and change (Etowa et al., 2007; Kemmis & McTaggart, 2000). We chose a participatory approach to ensure the outcomes of the research would be relevant to the Black community and to ensure the research was conducted in a manner that was culturally appropriate. Community members from the Black community, specifically research team members, were involved in conceptualizing the project, deciding on research methods, and analyzing data. Ensuring that knowledge gained from the research was used by the community to initiate change was a key objective of the research.

Participant Selection

Participant selection in this project was achieved through purposeful and snowball sampling. Purposive sampling selects participants based on unique characteristics of interest to the research questions (Silverman, 2000). Atkinson and Flint (2001) describe snowball sampling as a technique for finding research subjects where one identified participant identifies other potential participants. Specifically, inclusion criteria were established prior to recruitment. All participants had to be African Canadian. Each participant was required to be providing care for someone terminally ill at the time of the interview or to have provided care within the past 5 years to someone who died but not more recently than the past 6 months. Participants were recruited from a historic Black community located in the Halifax Regional Municipality. For many African Canadians living in Nova Scotia, the local church plays an important role in family and community life. It is for this reason that we chose to recruit our participants from the local church community. Six participants were recruited to participate in the focus groups: 4 women and 2 men, all in the age range of 50 to 70 years.

The Black community in Nova Scotia is small, and the social networks are close-knit; therefore, to protect their identity, additional demographic and other potentially identifying information is not provided. A community leader was identified to serve as the research facilitator in the community. The Research Facilitator recruited the participants and conducted the focus groups.

Focus Groups

For this research, we used focus groups as our primary means of data collection. In essence, focus groups are a form of group interviewing. Fontana and Frey (2000) describe focus groups as an ideal method for qualitative data collection where a particular phenomenon is of interest to the researcher. In this case, the phenomenon of interest is the process of providing care for a loved one with a terminal illness and their knowledge of available palliative and end-of-life care services. 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, aiding in recall and the "group process," and aiding problem solving and strategy development (Fontana & Frey, 2000). In this research project, the focus group members were well known to each other because of close family and social networks. The group interview process facilitated individuals sharing their own story.

The research was divided into four phases. The first three focus groups (representing the first three phases) took place at intervals of approximately 1 month, whereas the community meeting took place almost 1 year after the conclusion of the third focus group. In the fourth phase, the community was invited to participate in a town hall meeting to hear the findings of the research (see Table 1).

Ethical Considerations

This research involved participants who knew each other, and thus issues of confidentiality were a concern. Informed consent included an understanding that personal information would be shared in the focus group sessions, and that participants would respect the confidentiality of other participants. The Research Ethics Board of the Capital District Health Authority, Halifax, Nova Scotia, approved this research study. The research was conducted in the period from 2007 to 2009

Analysis

The research team (with the exception of Victor Maddalena) is African Canadian. The African Canadian members of the research team are all recognized as leaders in the Black community either as researchers or as social advocates. The research team's in-depth knowledge of the Nova Scotia's African Canadian community and Black culture was instrumental in identifying the research questions, the approach to data collection, analysis of the data, and dissemination. We approached this project with a common understanding that qualitative research is a "situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible" (Denzin & Lincoln, 2005, p. 3). The participants and the researchers explored the meaning of providing care to a loved one at end of life. As in our previous study, the research team approached the study with the belief that story telling is an integral feature of Black culture and a powerful means of communicating lived experience. The stories of the participants, their experience and wisdom, were shared with the research team, and we, in turn, reflexively interpreted this experience through our own subjective experiences.

Each focus group interview was audiotaped and transcribed verbatim. Transcripts were coded manually by three members of the research team for dominant themes and for unique

or novel narratives. A 1-day team meeting was held to discuss our individual coding of the transcripts. Differences in coding and analysis were discussed and resolved through consensus. We analyzed the data using thematic analysis and discourse analysis (Coffey & Atkinson, 1996). We understand discourse analysis to be an approach to analyzing language in the form of text to derive meaning from these data (Fairclough, 1989). Discourse analysis "emphasizes the way versions of the world, of society events and inner psychological worlds, are produced in discourse" (Potter, 2004, p. 202). In this regard, the social context in which narratives are situated is of primary interest (Cheek, 2004). The data from the focus group interviews—their stories and beliefs—were examined through the lens of African Canadian culture. The researcher's "insider" knowledge (Acker, 2001) of Nova Scotia's Black community played an important role in the formulation of the project, data collection, and analysis of the data.

Findings

Findings are presented below based on the four phases. Subthemes are identified and explained in more detail.

Phase 1: Learning From the Community: Caregiver's Experiences

Caregiving: A family affair—Discussion arising in the first focus group characterized caregiving during terminal illness and end of life as a "family affair." There was a general expectation that close family members and community provide the majority of caregiving in the home setting rather than in an institutional setting. Personal sacrifice to fulfill the caregiving role was common.

> I quit my job to look after her because I was there all day until about 2:30 until he came home, he more or less took over and I would go back in the evenings when it was time to get her ready for bed. We didn't have homecare, because homecare was supposed to come but they'd only give us an hour and a half so we needed someone there with her for the rest of the day, so I decided to quit my job and look after her without homecare or anything like that.

Caregiving can be a stressful life experience. A caregiver is often dealing with multiple burdens ranging from losing someone they love—in many instances a life partner—to the stress of caring for someone who is ill, suffering, and in pain. In addition, they are often dealing with physical strain, economic strain, and a loss of hope. Whereas most of the care-givers in our previous study were women, in this study, two of the six participants were men. Even in the case of male caregivers, female relatives or community members continued to play a significant role in the care of their loved one.

Although family-centered care in the home setting is common, there are times when the caregiving burden was too much for a family to manage. In these instances, their loved one was admitted to a hospital or a nursing home setting. Experiences with the formal health care system were generally reported as being positive.

> [Being admitted to hospital] … was a good experience and like I said it was good thing because what would you do without it? Because when you get the steps, and

my mother was at that step (stages of sickness) when she said, "This is it I want to go to the hospital. You guys can't do anything more." So I called my sister at work and she said, "That's okay, you sure she wants to go?" She said yeah, I want to go, you did all you could for me and that was it. She come, signed the papers and then took her in that night and at 9 o'clock she was gone. They did wonders. And the palliative care was set up there. When she arrived everything was set up. And 9 o'clock that night she was gone.

Financial burdens—Among the participants, financial strain associated with the care of their loved one was a common experience. Examples of causes of financial strain included remodeling of the home setting to accommodate various degrees of disability, needs for special appliances (e.g., beds, raised toilet seats), prosthesis, or aids for mobilization.

… with the remodeling things I had to do in my house, it was very costly. I had to put in a higher toilet. I had to put in bars [in the bathroom]. Just a few weeks ago I had to buy new furniture … I had to buy one of those recliners chairs that cost a lot of money … I had purchase new things because when he [husband] sat down he couldn't get up. We asked the lady, she was a physical therapist, and my husband said to her one day, 'you telling us we have to do all this (home changes) but where's the money'?

Lack of respite—Finally, participants expressed a lack of respite and bereavement care. Participants expressed the view that despite assistance from family and community, they felt the unrelenting burden of care with little reprieve.

… we had to take turns in the night. It was very hard. The next day you were so tired. You would think that you would get rest by taking turns, but you weren't getting rest. You were tired because you were up all night. And then it was a lot of going back and forth, to go get blood work done or you have to go get ultrasounds, like different things like that.

Bereavement care was similar to respite care; despite assistance from family members during the time of their loved one's illness and death, there were few opportunities to access formal bereavement care.

I trusted in the Lord. And he sustained us, and I said, "whatever You will …" That was it. I had no support.

Phase 2: Information Session by Capital Health Integrated Palliative Care Service

In this phase, the objective was to provide focus group members with a formal presentation describing the various kinds of palliative and supportive care services available through the Capital District Health Authority Integrated Palliative Care Service. The presentation was prepared and delivered by representatives (a physician, a registered nurse, and a representative from the provincial government) from the Palliative Care Service. Although the objective was to provide information on services and how to access those services, it turned out to be a dialogue between focus group members and the representatives from the Palliative Care Service.

In general, the focus group members found the presentation very informative. Representatives from the Palliative Care Service also learned about the lived experiences of the caregivers and their lack of knowledge about available services. Focus group participants expressed limited knowledge of palliative care services, and the professionals were not aware that palliative care services were not well known in the community. Both groups (the professionals and the care-givers) learned much about each other, and the ensuing dialogue was productive.

Phase 3: Giving Back to the Community—Making Change, Identifying Next Steps, and Knowledge Translation

Focus group participants noted that the "system" is generally unaware of the experiences of African Nova Scotians, especially at end of life. The most likely reason for this is because so much of the care during terminal illness and at end of life is done at home, by family members, and not in health institutions.

Accessing information about palliative care—Focus group participants were disappointed that information about palliative care services is not getting to the community. Participants identified the need to explore different ways of communicating with the community. In general, the focus group participants found the information they received was very helpful. As one participant stated,

> I thought it was very interesting. I found out where to go to get things for our family and who to talk to and it was just good to sit around and discuss.

Another participant stated,

> Very interesting. I learned a lot during that class I attended. I picked up things I didn't know.

Another participant stated,

> We're glad that we had people come along and tell us things and we learned a lot and [sharing] my experiences with different cases. But we hope this continues. And we want to see something to come out of it in the community.

Services that were of most interest to community members were those that supported their preference to care for their loved ones in the home setting. Examples included assistance with transportation and financial burdens associated with providing care in the home, meals on wheels, pharmacy delivery services, respite care, and home care. Services that could be brought to the community (eliminating the need to travel into the city), for example, blood collection clinics, blood pressure clinics, and flu shot clinics among others, were also identified. Reliance on hospital or institutional care was viewed as a choice of last resort. When someone is moved from the home setting to the hospital to receive care, it is usually at the "end stage" or when there is a crisis.

> That's how we kinda measure that people are really sick 'cause then they go to the hospital. You're like, they must be really bad, because they are at the hospital.

Another participant stated,

> A lot of people mention … keep them home as long as you can 'cause you know when they go into that palliative care they don't come out …

Caregivers were often aware of services, for example, home care; yet concern was expressed that their loved ones did not want "strangers" in their home. Or in the event they do have home care services, they worry about the inconsistency of caregivers.

> That's what we are saying because how we're raised … we're not comfortable having outsiders in our house. So that's part of the struggle. It's like, who do you have coming into my house? It's bad in a way, because if somebody comes and he don't know them, he won't let them in …

Another participant stated,

> That's my Aunt! If a man showed up, she'd send him home. She told them when she was doing the papers, "never send a man"!

Focus group participants who were receiving assistance from various professional care providers had high praise for their work.

> And you'll have the same person all the time (care worker) and the ones I've met were very nice. The thing is patience. To do that job you have to have patience upon patience. And I really give them all the praise for it because they really have patience. Sometime you say oh my God! You just want to throw the towel in and give up! You just wish for the Lord to take you and get it over with! By them working with you it helps you and it teaches you so much. And it's not easy for them as well. You know you might say it's hard for yourself and what you go through but don't let anyone fool you; it's not easy for them too.

Another participant stated,

> … and the expenses and all the dressings and everything and they bring it right to your door. And you get good care. (Family member receiving home wound dressing by home care staff)

Sharing information with other Black communities—Focus group members expressed the need to get information about services into the broader community. They acknowledged that there were people in the community who needed services, but many were not aware of what was available.

> Because a lot of people are sitting home by themselves lacking in a lot of things they could have access to. Because I've known people I have spoken to and they say, "well I can't get any help." But its where to go and how to get it …

Another participant stated,

> … so we were thinking it would be a good idea to have a meeting for the whole community so whoever is interested could come and know about a lot of these things.

Although we were not able to specifically determine whether new knowledge of palliative and end-of-life care services would increase utilization, participants indicated an interest in

accessing these services. In addition, participants felt this information would be helpful to families providing care in the home setting.

Various suggestions were put forward to communicate information regarding services available to support care in the home, including, for example, community information sessions, word of mouth, e-mail, and using the community and church newsletters to share information.

In the ensuing discussion, there was considerable emphasis on the need for the community to rise to the challenge of meeting community needs, rather than relying on institutionalized care. For example, participants identified the need for a locally run program that could provide cooked meals to individuals who required assistance in preparing nutritious meals.

Phase 4: Community Meeting

As part of the PAR process, bringing information back to the community to share the findings was a way of "completing the circle." A town hall style meeting was held in the autumn of 2009 to present the findings of the research project with the community. Fourteen people attended the meeting. The specific objectives of the community meeting were to discuss the research project generally, present the findings, validate the community experiences with end-of-life care and accessing appropriate health services, explore ways to share the findings among other Black communities in Nova Scotia, and examine ways to engage policy and decision makers to improve access to services.

Attendees were keen to be informed of the results of the study and to offer suggestions for follow-up and ideas for change. One benefit of the community meeting was that several of the attendees were also part of the focus group, and this served as a way to authenticate the data and findings through "member checking."

Following the presentation of the key findings, participants engaged in discussion of ideas for follow-up. They expressed frustration about the lack of resources in their community and their desire to lobby Capital District Health Authority for better services, including having a mobile health clinic. They also want more services that would support caregiving in the home setting, including, for example, meals on wheels, pharmacy home delivery, and home care services among others. There was an identified need to assess and provide these supports earlier in the illness journey. Participants also wanted to see a community health worker assigned to their area, who could provide information and referrals to health and social services. They also expressed interest in meeting with their local politicians and health service providers so they could inform them of their needs and community goals. As part of the PAR process, and to bring about policy change, a meeting—bringing together local politicians, health department officials, and palliative care providers—was held in October 2011. In the interim, a two-page brochure is being prepared to provide a summary of the research and to provide a list and brief description of health and support agencies with contact information.

Discussion

Our findings are consistent with previous research that examined the role of knowledge in decisions relating to end-of-life care in the Black community. Specifically, although Black families prefer providing end-of-life care in the home setting, lack of awareness of palliative care services and a lack of understanding of service availability are significant barriers to accessing services (Born et al., 2004; Rhodes et al., 2006; Taxis, 2006; Volandes et al., 2008). This in turn affects decision-making practices at end of life. Cultural traditions of family caregiving in the home setting are an example of personal decision-making practices that affect end-of-life care. This presents an opportunity for palliative care services to identify ways to support families in their desire for home-based care.

One possible reason why palliative care services have not responded to the unique circumstances of the African Nova Scotia community is because caring for loved ones in the home setting is integral to Black culture. This pattern of care, however, is likely the result of longstanding systemic racism dating back to their initial settlement in the province when health care was for the privileged. Thus, care delivered by family members in the home setting was a necessity and not a choice. The health system's continued neglect of health issues in the Black community arises in part due to a lack of knowledge by decision makers and a lack of processes to assess and understand health needs facing the African Nova Scotians (Maddalena, 2005).

Conclusions

In the Black community, caregiving at end of life is typically provided by family members in the home setting. Community members in the role of caregivers have limited information regarding available services to support end-of-life care in the home setting.

The "system" is generally not aware of the lived experience of African Nova Scotians, especially at end of life. This is likely because so much of the palliative care is done at home, by family members, and because Black communities had to become self-reliant in providing for family needs. The health system lacks effective processes to engage the Black community with the aim of assessing, understanding, and attending to the health needs of African Nova Scotians (Maddalena, 2005). Information about palliative care services is not filtering down to these communities in a way that is meaningful to families dealing with terminal illness and end of life. In cases where families are knowledgeable about services, families tend to self-select services that assist them in providing care in the home setting. Opportunities for future research include a further exploration of how professional caregivers in palliative care services understand and attend to the end-of-life care needs of vulnerable and marginalized populations. Findings from this study support the view that culture plays a significant role in how families attend to end-of-life issues (Kawaga-Singer & Blackhall, 2001). There is a need to explore more effective ways of engaging Black communities in dialogue to identify palliative care needs for families and their caregivers.

Acknowledgments

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Table 1

Description of Research Phases/Focus Groups

Phase	Key Objective	Key Questions/Content
Phase 1: Learning from the community	The objective of this focus group was to engage participants in a general discussion about their experiences as a caregiver for someone who was terminally ill and dying. In particular, discussion focused on their use and knowledge of palliative care services available to support them while providing end-of-life care in the home setting.	• Tell me what it has been like caring for your loved one who is (or was) ill? • Who has been involved in the care of your loved one? • What kinds of challenges did (are) you and your family face while caring for your loved one? • What kinds of services (health, social, and community services) did you access to support your loved one? • What kinds of supports did you access after your loved one died? For example, bereavement, counseling, emotional support? • What kinds of services are available to you in your community to help you and your family while you are caring for your loved one? • While you are/were providing care for your loved one, did/are you using programs such as employment insurance, social services support, compassionate care benefits, etc.? • What kinds of community services are available to help you (e.g., church, social groups, etc.)?
Phase 2: Education session on services and support for end-of-life care	In this phase, focus group participants were provided with an educational session by representatives from the Integrated Palliative Care Service of the Capital District Health Authority. The presentation described health and social services, including palliative care services to support families caring for a loved one at end of life.	A presentation was provided by representatives of the Integrated Palliative Care Service of Capital District Health Authority. Descriptions of services (including in-hospital palliative care, in-home palliative care, home care, and other health and social service benefits). Information on how to access services was also provided.
Phase 3: Giving back to the community—Making change, identifying next steps and knowledge translation	This phase had two objectives: First, to engage the focus group participants in an evaluation of the supportive and palliative care services described in the education session (Phase 2). More important, the discussion focused on whether those services would be used if they, currently or at some point in the future, found themselves in the role of a caregiver. Second, discussion focused on exploring ways to develop supports that are culturally competent and that would assist families to provide care in the home setting.	• What are your thoughts on the information that was provided to you in the educational session (Phase 2)? • What is your knowledge/opinion of services that are available to support palliative and end-of-life care? • Are these services that you would use? Why? Which services do you feel would be most beneficial? Why? • Do you feel these services would be helpful to you as a caregiver? • What kinds of services would you like to see available to you and your family (that are currently not available to you) to help you provide palliative care for your loved one?
Phase 4: Community meeting	As part of the participatory action research process, a community town hall meeting was held to discuss and validate the findings from the research project.	Following the presentation of the key findings, participants engaged in a discussion to explore ways to take the research findings and move toward action and engaging policy makers to bring about change. Key question: What are some ways that we can make sure the other Black communities get this information regarding palliative care services?