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Carrying the Burden: Perspectives of African American Pastors on Peer Support for People with Cancer

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Abstract

For African Americans facing advanced cancer, churches are trusted sources of support and ideal settings to improve access to supportive care. The Support Team model enhances community support for practical, emotional, and spiritual caregiving. We report on focus groups with pastors of 23 Black Churches and explore their perspective on the Support Team model for church members with cancer. Pastors describe the needs of church members facing cancer from a holistic perspective and recognize opportunities for synergistic faith-health collaboration. The results of this study indicate potential benefits of the Support Team model in Black Churches to reduce silent suffering among individuals facing cancer.

Introduction

Persons living with serious illness like cancer experience physical, emotional and spiritual suffering that may affect their quality of life (Mori et al., 2011). For African Americans, this

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suffering is exacerbated since they also face barriers to early cancer diagnosis and potentially curative treatment, and experience higher rates of advanced cancer than other racial or ethnic groups (Freeman et al., 2000). Upon receiving treatment for cancer, African Americans, compared to whites, experience less effective treatment for pain (Cleeland et al., 1997; Cleeland et al., 1994) and are less likely to have advance directives or communicate their preferences about life-sustaining treatments (Borum et al., 2000; Haas et al., 1993; Mckinley et al., 1996).

Even with optimal medical treatment, the holistic needs of individuals with cancer transcend the boundaries of professional care. Patients living with cancer, and their families, have complex needs that challenge their psychosocial and spiritual well-being and ability to engage in health care decisions (Mori et al., 2011). Previous literature acknowledges the Black Church as a mediator between African Americans and the health care system (Giger et al., 2008; R. Taylor et al., 2000). Considered inaccessible or unaffordable, the conventional healthcare system is often reserved for emergency healthcare by many African Americans (Chandler 2010; Giger et al., 2008; Levin 1984).

Among the African American community, the church is commonly perceived as a trusted and accessible setting for resources and unconventional care (Levin 1984) and the pastor as a valued ally in bridging care disparities. Within the medical and academic communities, the Black Church is commonly recognized as a credible setting for health promotion, prevention, and screening (Ammerman et al., 2003; Ammerman et al., 2002; Baskin et al., 2001; Caldwell et al., 1994; Campbell et al., 2007; Campbell et al., 2000; Demark-Wahnefried et al., 2000; Goldmon et al., 2004; Hatch and Derthick, 1992; Hatch et al., 1993; Hatch and Voorhorst 1992; Kegler et al., 2010). Though the care needs may be even greater, healthcare collaborations with faith organizations following diagnosis of serious illness are less common.

Healthcare providers and pastors have mutual missions to reduce unnecessary suffering among those facing serious illness. Faith-based organizations have a tradition as the center of comfort, guidance, and inspiration during potentially life-threatening illness. As gatekeepers to the Black Church, African American pastors, revered as spiritual and life guides, witness and hear about the cancer experience as it affects the daily lives and households of those diagnosed. Prior public health studies have engaged churches in community-based interventions to improve access to cancer screening but have rarely explored the potential of the church-health provider partnership for African Americans facing advanced cancer (K. Taylor et al., 2003). One such partnership that shows promise is the Support Team model.

The Support Team model is an innovative peer support model. The Support Team model developed in 1994 by Malcom Marler builds upon the social capital of existing groups to meet the support needs of one or more individuals (Buys et al., 2011; Stevens et al., 2009). Volunteer members of each team receive training and orientation based upon four guiding principles: (i) do what you can, (ii) when you can, (iii) in a coordinated way, and (iv) with a built-in support system. Teams are encouraged to provide practical, emotional, and spiritual support to individuals with chronic or serious illness. The structure of the support team fits

well with the altruistic values of faith communities. Though the model has been widely used, only two peer-reviewed publications describe its use within faith communities to deliver Meals on Wheels (Buys et al., 2011) and offer support to caregivers of dementia patients (Stevens et al., 2009).

Since 2000, the nonprofit organization Project Compassion has facilitated support to individuals dealing with chronic and terminal illness through the support team model. In 2007 Project Compassion joined investigators from the University of North Carolina-Chapel Hill, the Lineberger Comprehensive Cancer Center, Duke University Divinity School, and two community health advocacy organizations in a partnership to extend the support team model to African Americans facing cancer through an initiative called the Circles of Care (Hanson 2009; Hanson et al. Accepted 2012). Community volunteers coalesce to provide practical, emotional, and spiritual support as a united support team, after receiving training and information on how to connect to area health resources for cancer care, palliative care and hospice. To understand the potential for Black Churches to extend supportive cancer care, community-academic partners in Circles of Care led semi-structured group discussions with pastors in order to 1) explore the supportive care needs of African Americans with cancer as perceived by pastors and 2) describe the characteristics of churches that do or do not choose to create volunteer support teams.

Methods

Recruitment

In a three-county region of central North Carolina, investigators recruited pastors serving predominantly African American congregants to participate in one of four “lunch and learn” semi-structured focus group discussions. Pastors were identified through contacts with local ministerial alliances, a church research network (Corbie-Smith et al., 2010; Goldmon et al., 2004), and a local nonprofit advocacy and health education organization addressing health disparities. A total of 102 pastors were mailed a letter and received follow-up calls inviting participation in the focus group session. Pastors received a $40 gift card following the session.

Data Collection

The study design used a semi-structured focus group discussion format to elicit pastor perceptions of supportive care needs of congregation members diagnosed with cancer and to introduce the volunteer Support Team model as a potential approach to meet these needs. All focus group discussions were conducted between September 2010 and January 2011 in the midst of recruitment and training for the Circles of Care intervention. Pastors watched a brief slide and video presentation about the model and preliminary evaluation research results. The Support Team model was defined as coordinated volunteer community support for individuals suffering serious illness and pastors heard examples and testimonials about its use in cancer care. They engaged in an audio-taped discussion led by an experienced moderator and guided by 4 key questions:

- Beyond medical care, what are the needs of someone diagnosed with cancer?

- How do members of the church reach out to them?
- What situations make it easier or more difficult to get care needs met?
- How is the support from the pastor or church different from the support from a doctor or cancer center?

At the completion of each discussion, pastors responded to a brief written survey to provide information on their age, gender, educational attainment, years of experience, additional vocation status, and characteristics of their church including year founded, denomination, active membership, and number of paid and unpaid ministers. They responded to 4 Likert-scaled items about the appropriateness of communicating in the church setting about support for persons with cancer. In the six months following the lunch and learn session, all participating pastors were offered support team training for their congregations. Pastors expressing interest in the Circles of Care Support Team model were contacted by the Circles of Care Coordinator and offered free consultation and training for the congregation.

Data Analysis

Audio-taped focus group discussions were transcribed verbatim, and entered into the qualitative software program, Atlas. ti, version 6.0. Individual speakers were distinguished but not identified by name or church affiliation. Three investigators independently read the transcripts and identified potential themes and codes within each topic grouping. They met and discussed themes and codes until reaching a consensus. Two investigators then coded all transcript text, and discussed coding decisions until they agreed on unified codes. Survey results were summarized using simple descriptive statistics and stratified by whether or not each congregation engaged in support team training prior to or following the pastor discussion session. All participants provided written consent and all study procedures were approved by the University of North Carolina at Chapel Hill Institutional Review Board (IRB).

Results

Characteristics of Participating Pastors and Churches

Twenty-three pastors representing 23 churches participated in the focus group discussions. The majority were African American men (Table 1). One third of participants described their role as bi-vocational and reported part or full-time employment outside the church setting. Both novice and seasoned pastors participated in the discussion sessions and identified their congregations as primarily urban and well-established in their communities. Pastors served a wide range of congregational sizes across various denominations, though Baptist (42%) and non-denominational churches (19%) were most common in our sample. Their churches offered a variety of health-oriented resources within their congregation such as health ministries and health fairs and screenings. When asked about their perceptions on settings for discussions on cancer support, pastors supported sermons and one-on-one conversations as appropriate settings and remarked that church members would be similarly receptive. In comparison, one-on-one settings were perceived as more appropriate settings to discuss cancer support for both pastors and members of the congregation.

During the discussions, 15 pastors expressed interest in the Support Team model. Ten of these pastors participated in follow-up conversations about the Support Team model and allowed brief presentations of the model to be shared with their membership. Representatives from seven churches participated in either a half-day Support Team member orientation session (55 individuals) or a one-day team Support Team leadership session (eight individuals) prior to or following the pastor discussion sessions. Each discussion group included at least one pastor whose church membership participated in support team training. Ultimately, six of the seven churches who participated in the support team training implemented a support team within a six month period of the training. In summary, two thirds of pastors saw the Circles of Care Support Team model as a good fit for their congregation, and a third of those churches participated in the training and developed support teams.

To meet the second objective, churches that did or did not adopt the Support Team model, defined as participation in Support Team model training, were compared on several characteristics – size, denomination, presence or absence of health ministries. Churches actively participating in the support team training did not differ significantly in any characteristics from churches not participating; therefore, combined characteristics are presented (Table 1).

Pastors' Perceptions of Cancer Supportive Care Needs

Pastors' responses during discussions were categorized into four themes: 1) cancer care needs beyond medical care, 2) ways to reach out within the congregation, 3) barriers to church support, and 4) differences between support received in cancer centers and community settings.

Care needs beyond medical care—Pastors observed a variety of care needs beyond medical care encompassing the holistic needs of African Americans with cancer, their caregivers, and children. For the individual facing cancer, pastors witnessed situations in which physical, practical, and spiritual care needs were met and not met. While noting common threads in the types of needs, pastors cautioned against presuming that needs are always medical, suggesting, "You need to make sure, that if you're listening, that also their physical needs are being met…like food or, like trips to the doctor. Those kinds of things come up and they're really ignored because we, we focus on the condition of the individual, when there are other things about them that need to be done." Pastors identified financial assistance as a concern for the person with illness including both direct assistance and connections to agencies. They acknowledged the time sensitive nature of discerning those needs, describing experiences when members had remained silent until the burden was overwhelming, such as home foreclosure.

Assistance navigating the healthcare system was also identified as a care need. For some individuals, navigating the health care system and making decisions are complicated by limited health care literacy. As reflected by a pastor: "they do need help, some of them, understanding the language of healthcare. They don't understand what DNR is; they don't understand why treatment has to stop". This brief narrative depicts the impact limited health

literacy places on the patient or caregiver's interpretation of care received and their understanding of treatment options.

Pastors spoke of spiritual connection as a comfort that is needed but often compromised during illness. Speaking from personal experience with cancer, one pastor reflected and observed, "Since we're dealing with a spiritual body of people, one of the struggles is, 'How do I really tie my faith into helping me deal with my physical struggles?' ". Spiritual connection may be threatened not only theologically but also socially. Several pastors acknowledged that normal routines of church life may be disrupted when parishioners can no longer attend services. Whether disrupted participation results from decreased driving ability, increased fatigue, or feelings of anger, the individual with illness experiences a sense of loss ranging from the tangible and specific to more expansive aspects of spiritual connection, as described here: "There's the sacramental needs, whether it's anointing, Eucharist, or whatever it may be. That's certainly something they're concerned about because they can no longer participate as they once did as members of the congregation, members of the assembly. That's only one thing. Then of course their spiritual needs are broader". Unable to receive communion or Eucharist, attend services, or participate in choir or other ministries, individuals with illness can easily feel or become disconnected from the informal or formal support of other congregation members.

Throughout the discussions, pastors emphasized how the impact that the cancer journey has on the family unit, noting practical and spiritual care needs for caregivers and(young and adult) children who observe illness within their own families or the congregation. Support for the caregiver was identified as a concern when caregivers take on foreign roles such as managing physical care, communicating with family members, and understanding and making medical and financial decisions. As one pastor observed, "The person or the significant other, who may not have it, who is actually carrying the burden of caring for that person - a lot of times they experience a tremendous amount of stress as well, so we have to be mindful of what they're going through, as well as the person who has the disease. So, you know, even though we're focusing on the person that has the illness we also need to focus on the caregivers, especially the ones that are around them all the time". Pastors described this multidimensional role of *carrying the burden of caring* as stressful and potentially problematic. They described situations where alleviating strain on the caregiver and family unit could be provided through respite and assistance in managing new roles.

Acknowledging the impact of the cancer experience on younger and adult children, pastors noted "whether" telling children about illness is more clear than determining "when and how much" to tell children. Well-meaning parents may delay disclosure until after symptoms and signs are obvious or limit the details disclosed referencing cancer type and stage in order to protect their children from distractions and worry. Pastors also reasoned that decisions on details and timing should also be tempered with sensitivity the child may have about their own susceptibility to cancer -- "This is my dad… or my mother… when am I going to get it?" Pastors observed that children carry a burden despite attempts to protect them. Young and adult children may express feelings of anger when not privy to details and a sense of hopelessness when information is shared at point where it is too late to intervene. These feelings may be directed toward the parent, pastor, health care providers or others who knew

of the diagnosis and delayed disclosure. For some adult children the feelings of anger may be directed towards God. As God's representative, pastors sometimes felt they had to bear the brunt of this anger. With the diagnosis of cancer comes an "*abundance of questions and concerns and fears*. " For example, one pastor shared how adolescents within the church process progressive illness:

> "I think sometimes that we underestimate their strength and we underestimate how much they really are receiving when they're sitting in church, and hearing the messages. I know that it looks like they're texting and it looks like they're talking to each other, but you can download the bible right to your phone. And so, we sometimes underestimate what they can handle. We also, I think, underestimate what they're talking abou, because from working in youth ministry, they're talking about cancer. And so they're sitting in the congregation and they're saying, 'Well [NAME] looks like they're lost weight. I wonder if…' They're talking about it and they're thinking about it. We think we're somehow protecting them or helping them to get the information as we think they need it, when in actuality they've already discerned or noticed or whatever, that something is going on and they're wondering. I think it is incumbent upon us that they can come and ask. 'Reverend, I saw sister so and so and she looked like eggs.' And now, of course we have to be confidential-we can't talk about people's business-but at the same time we do have to find a way to include them in the dialogue as early as they're ready to be a part of the dialogue."

This quote exemplifies the impact of cancer beyond the family unit to the extended church family, the balancing act between respecting privacy and supporting needs, and the impact of avoiding discussion with youth witnessing illness. Young church members notice the deteriorating physical and emotional state of a church member who is losing weight and seeming unbalanced or scrambled, and are left to their own conclusions which may be accurate or perpetuate myths regarding illness. Pastors acknowledged talking about cancer within the church as a means to inform support needs of the individuals with cancer by learning from cancer survivors and caregivers within the congregation. More broadly, they referenced the communal setting of churches as places to help those yet to be diagnosed seek early diagnosis and needed support.

Ways to Reach Out—A second category pastors identified for showing support to cancer patients was sharing ways to reach out during illness. They discussed processes for notification of illness within their membership and approaches to extend support to church members who become ill. Their discussions about notification and extending support were marked by wide variation among congregations.

Pastors acknowledged variability in how they become aware a member who has a serious illness, their role in offering support, and strategies adopted within the church to offer support, noting " How it works at each individual congregation will look dynamically different". Notification about a congregant's illness could occur either through self-disclosure, family members or other church members. Methods for information sharing included disclosure directly to the pastor or other leaders such as deacons (one-on-one) or to

the church membership during bible study, through postings in the church bulletin (sick and shut-in list), or by word of mouth. Pastors agreed that they might not always be the first to know about illness. When they were alerted, their role could range from spiritual consolation, to respite, to delegation and garnering church support. Pastors recognized limitations to their roles noting, “It’s not that the pastor has more important things to do. But the pastor has other things, so many things to do.” Another pastor reflected on the sensitivity involved in delegation, emphasizing the importance of relationship between the pastor and congregants and among congregants themselves: “Some people have difficulty getting help from someone other than the pastor. ‘I want the pastor to pray for me, not you. ‘How do you address that?”

All participants agreed that having support during illness was important. Informally, members of the choir, ushers, stewards, trustees, deaconess, deacons or other officers and leaders might rally around ill members of the same committee or subgroup of church members. Another pastor described the role deacons play to identify and coordinate spiritual and practical support, acknowledging limitations if the needs expand much beyond basic needs. One pastor noted how systematic structure can aid pastors. One example provided was the Class Leaders ministry associated with Methodist denominations. The Class Leaders ministry is a Christian nurture and training method whereby Lay congregants are designated to serve as leaders of small groups (classes). Class leaders are then trained to nurture and support the spiritual growth of congregants. The size of the class and nature of interaction naturally help identify and support members’ triumphs and challenges.

Other pastors proposed the need to motivate or sanction the supportive capacity within their membership. Their observations categorized support in the church as traditionally maternal with the mothers of the church coming together as the ones caring for, nurturing, and visiting ill members. Reflecting on memories as a child, one pastor recalled, “When I was growing up my mom and the other mothers of the churches were the ones who went to see the sick, and took care of their need and what have you. That’s not happening today, you just got one or two.” Pastors recognized the Support Team model as a reinvention of this Christian stewardship role traditionally fulfilled by mothers of the church. As the church and our society have become more distant from traditional roles, this service has disappeared from many churches. Pastors described reluctance among members who hesitate to take on leadership positions because of their lack of confidence, structure, or their concern of becoming overburdened. One pastor coined this response as “*spiritually obese*”, where members perceive the church as a place to receive spiritual nourishment, yet still do not feel equipped or inspired as stewards of support for others.

Barriers to supporting church members—The third category of discussion by the pastors was around factors that complicate and limit supporting the care needs of members with cancer. The most common barriers discussed included concerns about privacy and spiritual conflicts regarding faith and illness. Privacy was identified as a barrier to meeting health care needs. Simply stated by one pastor, “Sometimes people go without the care because they don’t want anybody to know”. This dilemma abandons members of the congregation riding this conflict to suffer in silence. Dimensions of this silence span fear of cancer, shame of illness, or desire for autonomy and self-reliance. Pastors observed that

despite the growing number of cancer survivors, initial reactions to cancer diagnosis threaten survivorship and sense of hope. “When you hear the word cancer, psychologically people think that it is an automatic death sentence. And so, letting them know that through faith and medicine there is hope.” In addition to the fear described, this pastor reflected on how sharing faith and hope counteract the powerlessness of fear.

The need to protect one’s privacy may be fed by shame or paralyzing fear of additional loss. Pastors shared examples of when care needs go unmet as members juggle dealing with their illness and disruptions to other aspects of family life, like financial stability and spousal commitment. “It has a lot to do with the level of sharing that that particular individual will want to share. They might have a serious illness, but they might let you know spiritual superficial things like, I just need prayer, pray for me. But in the background it might be, about to lose your house or, or a spouse might be leaving um because they’re ill…” This issue of privacy is more complex when the care needs of the family unit are incongruent. Incongruent feelings about privacy, disclosing cancer status, or seeking support between spouses or parent and child, leave the needs of the person with illness or their caregiver sacrificed.

An additional barrier pastors discussed was individuals’ perceptions of the connection between faith and illness. Pastors identified the perceptions that unfaithful Christians get sick as an immense challenge to faith, communication about illness, and by default help seeking behaviors. As one pastor described,

> “Someone talked earlier about the relationship between faith and health, and faith and medicine, and communicating that it’s a lack of faith because you get sick, or because you have a challenge. There are many people that have done great things, that God has done great things through that died of sickness in disease…Hezekiah, he had a sickness unto death. So, sickness doesn’t mean that you don’t have faith and that you should not talk about it. So, getting that out in the air and out in the open so that people understand that in part it is your faith that helps you deal with the challenges in life, it doesn’t mean that you don’t have challenges, it just helps you understand how to deal with it.”

Pastors shared opportunities within their respective churches to overcome some of these barriers. They discussed the importance of member education regarding cancer care, serious illness and appropriate means of support. They discussed experiences bringing in guest speakers from hospice, funeral directors, and other local resources, responding to the “responsibility of the church to help members get prepared, [and] get in their mindset that they don’t need to wait ‘til the last minute”. Such efforts intended to educate the church community, correct misperceptions, eliminate fears, and provide advocacy tools were often described as poorly attended, yet positive experiences for those who did participate.

Differences between Supportive Care in the Community and Cancer Center— The fourth and final category for the pastors’ reflection was the differences in support received in the cancer center and community settings. Their responses distinguished spiritual support as important to the care needs of the individual but sparse in the cancer center. One pastor, who identified himself as a cancer survivor, summarized the variation in support

between the cancer center and community, praising the strengths of support from both venues as essential aspects of treatment.

> "[The cancer center] show[s] compassion and they show interest in you as a person, but they keep it in that realm of, for the most part. It's medical, which is where their strength is. So, you don't get so much the spiritual supporting base that you thought you'd get. You get love and care, and concern, which ties into it. But to get that spiritual uplifting, to get those kind of things that can come through a congregation or church, that does not come into play in the cancer centers and in the doctor's office… You get those exceptions, … if you've got a base and a support team and group in the church that now can provide you with the spiritual uplifting and encouragement, and assistance in other ways, I think that it brings about a better perspective for that individual, I think it also possibly prolongs the life, and the struggle that they may be going through…it makes it more tolerable."

This quote emphasizes the synergistic relationship between the church and medical care. Pastors emphasized the strength of the relationship and communication between those offering support and those receiving support as factors in determining the needs of the person and providing the comfort they need, when they need it. Other pastors reflected on the importance of being centered or maintaining a composed presence when interacting with members in need of support. By veiling their own anxiousness and temporarily overlooking their hurried schedules in order to sit with or listen to the caregiver or member facing serious illness, the pastors may create a more tranquil and comfortable environment, in which the member is more likely to be open and willing to talk. One pastor described the reciprocity of spiritual uplifting and presence, calling her church a "hugging church. You know when you come in you get a hug, you leave, you get a hug". Pastors distinguished comfort and presence as sources derived from community support that are built through relationships over time and not typically received in the professional cancer care setting. Without these relationships, those persons offering support risk "saying the wrong things, which challenges them instead of comforting them".

In addition to differences in community and cancer center care, pastors reflected on the similarities and synergy in supporting individuals with cancer. Both community and medical sources of care were perceived as limited by the person's participation in care. As one pastor explained "a lot of times pastors are sort of looked at as doctors sometimes, when it comes to spiritual things. We're caretakers, we write prescriptions, we tell you what you're doing wrong. What you have, and what you need to do to fix it. The thing is just like we don't follow doctor's orders, we don't follow the pastor's orders either." Pastors reflected on medical care and faith as synergistic despite being perceived as adversarial. They described their experiences communicating the holistic benefit of maintaining one's faith while concurrently doing, *"What the doctors say that you should do."* As some pastors recounted, "We're not asking them to abandon what the doctors are saying, but we're also encouraging them to hold on to their faith, because this is the thing that is going to see them through."

When discussing supportive care, pastors described the benefits of purposeful partnerships. Some pastors invited hospice and other supportive care representatives into the church setting for informational sessions. One pastor describes the quality of their partnership with

a local hospice organization, transition between support provided by church members and the hospice agency, and the benefit of the support provided extending to the family unit: "We have really good experiences with local hospice organizations, … there's the baseline care that the congregational members sort of just provide almost without thinking about it, it just, it just happens, but as the end of life nears and they sort of get beyond their level of experience or expertise. The hospice groups, have been phenomenally effective in helping the family, helping the patient, make some transitions…" In some instances, these partnerships developed from the expertise within the congregation. Pastors reflected on exploring and tapping into the diversity within church membership itself as a source for new partnerships for effective supportive care.

Discussion

During the piloting of a community-academic cancer center partnership for African-Americans with cancer, pastors participated in guided discussions to share their perspective on supportive care needs and the potential for community based support teams to meet these needs. Two-thirds of participating pastors believed the model was a useful innovation in supportive care, and one-third adopted the Support Team model within their congregations over the next 6 months.

While two-thirds of participating pastors expressed genuine interest and value in the support team model, all did not adopt the model. However, pastors did share contextual factors that suggest introducing the support team model was challenged by competing priorities. Three pastors were in the middle of transitions to new churches. Others noted that their health ministry was in the process of reorganization or that they already had a system in place that seemed to work.

The majority of these pastors served churches with health ministries. Both churches with and without health ministries adopted the model equally. Aspects that distinguish the support team model from health ministry are two-fold. First, the scope of a support team model differs from the scope of a health ministry. Because they are developed in partnership with a cancer center and community health organizations, support teams have training and access to cancer care information enriched by these connections. This distinguishing aspect of the support team warrants further study to describe benefits of the partnership. However, we expect strengthening connections and information access outside the cancer center will improve the likelihood that unresolved health concerns are redirected to the provider and treatment team. Secondly, the support team model is systematic. There is a systematic process for identifying individuals who need support, matching them with a team willing and able to provide support, and training the support team. Health ministries may or may not operate within systematic procedures. Health ministries may be profoundly supportive to congregants using current approaches such as health screenings, health fairs, and parish nursing. Alternatively and additionally, the Support Team Model may offer advantages to some congregations by increasing the number of individuals who are trained to provide practical emotional and spiritual support.

Peer-oriented supportive care approaches are believed to increase well-being (Hoey et al., 2008). The Support Team Model offers an innovative addition to supportive cancer care approaches which are more commonplace within cancer center settings, such as the peer support programs and support group. Lay health advisor and patient navigator models, the most common peer support model formats, pair individuals diagnosed with cancer with those who have experienced cancer with the purpose of providing one-on-one emotional support and information based upon personal cancer experience. The support group approach brings peers with a similar condition to a central location to mutually give and receive support to each other (Hoey et al., 2008). However, the Support Team Model assembles a network of peers who come to the individual to meet the individual's practical, emotional, and spiritual support needs in the home or surroundings familiar to the person with cancer. While the Support Team Model differs structurally from other peer approaches, the varying needs and preferences of individuals facing cancer, and their families, may be best served by one or a combination of these approaches.

Pastors described the supportive care needs of church members with cancer from a holistic perspective. Foremost, care needs are unique to the individual facing cancer. Pastors endorsed the importance of relationship and connection to identify and respond to the individual and their care needs. The emphasis is on providing care and support that is desired by the individual. The benefits of relationship are futile when assumptions about care needs are made and cancer overshadows focus on the individual. Existing literature recognizes strong social ties and relationships as one of the strengths and multidimensional roles of the Black Church within the African American community (Giger et al., 2008; Goldmon et al., 2004).

Secondly, pastors observe that carrying the burden of caring for someone with cancer extends meaningfully to the caregiver, children, and the church community. Parents diagnosed with cancer want to protect their loved ones and children from harm. Protectiveness inside the family and privacy outside the family may limit sources of support. This theme is similar to the emotional risk of disclosure found by Lopez and colleagues in a study of African Americans completing breast cancer treatment (López et al., 2005). Effective sources of supportive care must respect and attend to privacy concerns, and acknowledge the needs of the person with cancer as intertwined with their concerns for family.

Lastly, pastors provide insights into the potential synergy between medical and community sources of supportive care for cancer. Within the church, the pastor is revered as gatekeeper, endorser, and spiritual counselor. Within the medical system spiritual leaders, even those employed as chaplains, are rarely accepted as integral members of a multidisciplinary team supporting seriously ill patients (Cadge et al., 2011). In the healthcare setting, medical providers compartmentalize their own role as providing medical care while others provide holistic care, attending to the patient and family emotionally, spiritually, physically and logistically. In this study, pastors acknowledged the separate gifts of healthcare and community care, but also saw potential for synergy and collaboration.

Taylor (R. Taylor et al., 2000) demonstrated how strong organizational ties between faith communities and local organizations can increase referrals and appropriate access to conventional care. Strategies that express appreciation of pastors as co-providers of care and actively build partnerships between the faith communities and the healthcare system should be considered for future research. Lessons from church-health provider partnerships with primary care and mental health systems and faith communities provide useful examples (Aronson 1975; Tubesing et al., 1977). The support team model, as used in Circles of Care, facilitates this collaboration to ensure that practical, emotional and spiritual supportive care is available in conjunction with medical care for cancer.

Strengths and limitations

This study of pastor reflections on church-health provider partnerships in the context of serious illness revealed several strengths. There are important strengths in this study. Pastors and congregations are major sources of community-based support in cancer care, yet the perspectives of African-American pastors are rarely incorporated in supportive care programs. Our findings support the potential for the Support Team Model as a means to address supportive care needs collaboratively. Perhaps these findings also underscore the power of support team interventions in churches whose pastors are open to reflection on nontraditional forms of spiritual support and open to receiving basic information about patient and family needs. The results of these guided discussions provide pastoral insights in maximizing quality of life for African Americans with cancer, and demonstrate elements of congruency with medical providers.

We recognize limitations to this study. First, our sample size is small and consisted primarily of African American male fulltime pastors serving primarily Baptist congregations and may not be generalizable to a larger population of church leaders. Secondly, our discussion and survey elicited perceptions from pastors only and we are not able to compare their perspectives to those of church members. There are inherent biases when the primary data source is comprised of beliefs and perceptions; However, the subsequent acceptance of support team training and formation by one-third of these congregations provides some evidence of church membership endorsement of their role in supportive care for cancer. Finally, in a short time period, pastors received information on an innovative model of support, reflected on the support environments of the churches, and determined church interest in the model. Given a longer follow-up period with more intensive information-sharing, additional congregations may have adopted the support team training.

Implications and recommendations

The results of this study have implications regarding potential benefits of Black Churches as a source of supportive care to reduce silent suffering among individuals facing cancer. Over two-thirds of pastors agreed that the church is an appropriate setting for cancer health messages and for organized support teams; one-third took direct action and created support teams. While church members endorse the appropriateness of pastors posing health-related messages, health messages are not often present in sermons (Alcantara et al., 2007). Pastors recognize the “importance of connecting the biblical messages to health-related issues” (Williams et al., 2009).

Similar to the philosophy underlying the Support Team model, pastor perspectives on cancer support strongly suggests that no individual provider can meet the needs of someone with cancer. Nevertheless, healthcare providers and community sources of support have great potential for collaborative care. Future studies can extend understanding of the benefits of the Support Team model and other innovations in supportive care to improve the quality of life for African Americans facing serious illness with cancer.

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Table 1

PASTOR CHARACTERISTICS:	**(N=23) (%)* (Range)**
Male	18 (78%)
Age	
<35	2 (9%)
36-45	2 (9%)
46-65	17 (74%)
>65	2 (9%)
Education	
Bachelors	5 (22%)
Masters	10 (43%)
Doctorate	8 (35%)
Bivocational	7 (30%)
Denomination	
Baptist	11 (42%)
Methodist	4 (15%)
Nondenominational	5 (19%)
Pentecostal	2 (8%)
Other	4 (15%)
Pastoral Experience (Years)	
Total	21 (Average); 2-60 (Range)
Current church	15 (Average); 25-51 (Range)
Health Ministry Resources	
Health Ministry	18 (78%)
Auxiliary Ministry	8 (35%)
Parish Nurse	2 (9%)
Cancer Support Group	1 (4%)
PASTOR PERCEPTIONS:	
As a church leader:	
sermons (Very Appropriate)	15 (65%)
As a church leader 1:1 (Very Appropriate)	17 (74%)
As a church member 1:1 (Very Appropriate)	17 (74%)
As a church member in a support team (Very Appropriate)	15 (65%)
CHURCH CHARACTERISTICS:	
Church Member Age	
< 17 years	11% (Average); 0-30% (Range)
18-35 years	10% (Average); 0-30% (Range)
36-45 years	27% (Average); 0-100% (Range)
46-65 years	37% (Average); 0-100% (Range)

PASTOR CHARACTERISTICS:	**(N=23) (%)* (Range)**
Over 65 years	16% (Average); 0-60% (Range)
Number of Ministers	
Paid	1 (Average); 1-3 (Range)
Unpaid	9 (Average); 0-40 (Range)
Church Location	
Urban	14 (61%)
Suburban	8 (35%)
Rural	1 (4%)
Church Age	
	1937 (Average); 1812-2003 (Range)

* Percentages may not sum to 100% due to rounding.