They Lift My Spirit Up: Stakeholders’ Perspectives of Support Teams for African-Americans Facing Serious Illness

By

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They Lift My Spirit Up: Stakeholders’ Perspectives of Support Teams for African-Americans Facing Serious Illness

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Abstract

**Background:** Active social and spiritual support for persons with cancer and other serious illnesses has been shown to improve psychological adjustment to illness and quality of life.

**Objective:** To describe stakeholder perspectives of a community and church-based support team intervention providing practical, emotional and spiritual care for persons with cancer and other serious illness within the African-American community.

**Methods:** Support team members were recruited from African-American churches, community organizations, and the social network of individuals with serious illness, and paired with persons with serious illness. The intervention was evaluated using semi-structured interviews with 47 stakeholders including those with serious illness, support team volunteers, clergy and medical providers.

**Results:** Stakeholders report multiple benefits to participation in the support team including the consistency of support provided, support complementary to medical care, emotional and spiritual support, the extension of support to patients’ family members, and the fulfillment of service. Reported barriers to participation included desires for normalcy, independence, to initiate one’s own support, as well as perceived limitations in volunteer support and scope of training.

**Conclusions:** This qualitative evaluation provides initial evidence that a support team intervention helped to meet the emotional and spiritual needs of African-American persons with cancer or other serious illness. Support teams offer a practical approach to enhancing support within familiar social structures, including churches and other community organizations, and merits further study as a way to improve quality of life for persons facing serious illness.
Introduction

Persons with serious or potentially life-limiting illness have profound needs for supportive care, including practical, emotional and spiritual dimensions. The need for support may be magnified for African-Americans by disparities in health and healthcare access. Social support may aid psychological adjustment to illness.\(^1\) Descriptive research demonstrates that spirituality is an important element of supportive care for many persons with cancer and other serious illnesses.\(^2\)\(^3\) In particular, African-Americans may recognize more spiritual needs in relationship to cancer supportive care.\(^4\)^\(^5\) Access to culturally appropriate supportive care services, allowing integration of spiritual care, may improve quality of life for patients with cancer and other advanced illness.\(^2\)

Supportive care may be added to formal health care services, or may enhance existing community-based sources of support, as in peer support interventions. The support team model is an innovative form of community-based support adapted to address the needs of more seriously and chronically ill individuals. The basic model of a support team focuses on helping one person or family to meet a variety of needs and includes elements of peer support, focusing on the abilities of each team member who has a shared connection.\(^6\) Support team volunteers work together to provide practical, emotional, and spiritual support to a person who is open to receiving assistance.\(^7\) Volunteers offer to assist in a capacity they are comfortable with, in their own timeframe, but in a coordinated way. The support team model, which originated at the University of Alabama in 1994, has only been described in two peer-reviewed studies: a support intervention for caregivers of persons with Alzheimer’s disease\(^8\) and a church-based home-delivered meals program.\(^6\)

The aim of this current research is to describe stakeholder perspectives of an intervention that used the support team model of care for African-Americans living with cancer and other serious
illness. Using narrative interviews with diverse stakeholders, we sought to understand potential benefits of the support team intervention and the perceived barriers to participation.

Methods

Circles of Care Intervention

Circles of Care is a community based participatory research project which used the support team model to improve supportive cancer care for African-Americans. At the time of this evaluation, a network of 120 volunteers in support teams had been recruited and trained to create support teams to provide health information and practical caregiving to 41 African Americans facing serious illness. The Circles of Care project was conducted in a 3 county area of central North Carolina from July 2008 to July 2010. This project was led by investigators from University of North Carolina at Chapel Hill Schools of Medicine and Public Health and Duke University Divinity School, in collaboration with three community-based non-profit service organizations – the Community Health Coalition, Project Compassion, and CAARE, inc. Community members provided insight during the conception and implementation of the project as contributing members of a community advisory board.

Support Team Development

Support team members were recruited from African-American churches, community organizations, or the social network of the individual with serious illness. Volunteers elected to participate in a 3-hour team member training or day-long team leader training. Content included information on physical, emotional and spiritual pain, supportive approaches, palliative care and hospice and advance care planning. In leader training, participants practiced team-based approaches for communicating with, advising, and supporting persons who faced serious illness. Support teams included 6-10 trained volunteers who agreed to work together to support one or more individuals with advanced illness. Support team were matched with individuals
requesting supportive care based upon geography, existing relationship between individuals and the interest and skills of team members and identified support needs.

**Data Collection**

**Participant interviews**

Stakeholders were asked to participate in semi-structured interviews. Eligibility criteria included individuals age 21 or older who had prior experience with the Circles of Care support team project. Stakeholders were approached following engagement with the support team model and included volunteers who participated in training, persons who received assistance from a support team, those who considered but refused assistance from a support team, family caregivers, and clergy or health care providers referring to the program. No other eligibility criteria, including cancer type or stage, were used. Purposive sampling methods were used to guide the selection of participants. All eligible stakeholders were invited to participate; enrollment continued until each stakeholder group was represented by more than one participant.

Interviews were semi-structured, conducted in a private setting, and audiotaped. Interviewers were trained to use a written interview guide structured around these key questions: “What does a support team mean to you? How does this support differ from getting help at a cancer center or doctor’s office? Do people facing serious illness need support?” These questions were followed by probes exploring practical, emotional, spiritual support, quality of life, advocacy, and help with cancer or disease-specific resources. At the conclusion of the interview, participants were asked if they had recommendations for improving the support team model.
Participating support team members and persons with serious illness provided demographic and health data in a brief written survey at the time of study enrollment. They gave verbal informed consent for the use of de-identified descriptive information. Some persons with advanced illness elected to have members of their support team or family members present during their interview session. All research methods were reviewed and approved by the University of North Carolina at Chapel Hill School of Nursing and Public Health Institutional Review Board.

Qualitative Analysis

Audiotaped interviews were transcribed verbatim and redacted of identifying information. The final transcripts were reviewed for accuracy by the research team and the data were imported into Atlas 6.0 for coding and the construction of memos.

Analysis methods used a grounded theory approach to explore and organize themes. All transcripts were read by three investigators who led the analysis. Readers used iterative consensus coding to identify initial thematic groupings that emerged from the interviews. Categorical codes were defined in a series of consensus discussions, including support team barriers, support team benefits, facilitators of support teams, support team supplementation of medical care, support team unique qualities, call to service, recruitment, cancer journey, and connection. Once a unified coding scheme was agreed upon, two readers applied the codes to all transcript text and the third reader resolved any conflicting codes. All readers then reviewed coded qualitative transcripts and constructed memos to represent a synopsis of the data representing a single categorical code.

For the analysis presented in this paper, the codebook and all memos were reviewed to address the objective of understanding the benefits and limitations of the Circles of Care support team
intervention. All coded text was reviewed to gain further insight into thematic groupings. Selected themes, derived from subgroups of the categorical codes, were explored in depth for the purpose of the analysis. All text supporting benefits and limitations of the support model were examined, and illustrative quotations selected with attention to inclusion of the perspectives of support team members, persons with advanced illness, clergy, and medical providers.

**Results**

A total of 47 individuals participated in the semi-structured interview sessions. (Table 1) Most participants in the interviews were African American (86%) and female (77%). The age range of participants was from 20-89 years of age. Participants’ roles in the Circles of Care project included support team volunteers (52%), person with advanced illness (19%), medical providers (11%), caregivers (10%), and clergy (8%). Two persons with advanced illness considered but refused assistance from the support team model but agreed to participate in interviews. Six participants could be identified in more than one role in the Circles of Care project; for example, one participant was a member of the clergy and also a support team member. Three of the twenty-seven support team members also identified themselves as cancer survivors.

**Perceived Benefits of the Support Team**

Stakeholders described many different views on the benefits of the support team. Major themes regarding benefits were provision of *consistent coordinated support, complementary to medical care, provision of emotional and spiritual support, extension of support to family,* and a sense of *fulfillment in service* for those who volunteer. Each theme is described below in more detail, with related quotations from interview participants.
Consistent Coordinated Support

Interview participants describe several perceived gaps in the support provided by traditional medical care, and reflected on ways the support team addresses these gaps by providing consistent and coordinated support. Deficiencies in support related to medical care were described in terms of logistical limitations and lack of response to expressed needs. The support team was perceived to be a necessary facilitator and complementary to medical care. Several support team members voiced concerns that care and support should be structured to come to the person with serious illness and extended beyond the traditional hours of business. “Well I think a lot of the support groups at different facilities, especially a doctor’s office or a cancer center, they’re designed for the patient to come to them in most cases … a lot of these support groups at the cancer centers and the doctors’ offices, don’t get utilized to their full potential because that requires that person to come out.”

Another support team member emphasized the importance of support at any time of day, saying “They [Circles of Care support team] make sure that the person receives the support they need, psychosocial, whatever kind of support they need beyond the, the business day.”

Other participants with advanced illness perceived the benefit of the support team as the consistency of support for example, “… One thing about the Circle of Care, if they say they’re going to do something, they [are] there”.

Complementary to Medical Care

Stakeholders also found support teams beneficial because they complemented, but did not replace, formal medical care services. Many stakeholders who were interviewed perceived a gap in emotional and spiritual support for persons living with advanced illness that could not be
filled by the care offered by medical providers. A support team member commented, in reference to helping a person with advanced illness, “…if she had other people to facilitate some of those activities, she would have a much richer and much more meaningful life at home despite dealing with her cancer and cancer pain. None of those things are things that doctors and nurses can help her with.”

According to support team members, the support team provides assistance in companionship and patient advocacy and may even improve the perceived quality of care for the person with serious illness. For example, one support team member said, “. . . People that have someone to talk to, someone to help write down discussions that occur between the physician or provider and the patient, it’s a second set of ears, a second set of shoulders to lean on and those people tend to do a lot better through treatment as well as in the recovery phase.”

Some stakeholders also described the ability of a support team to integrate practical support with emotional and spiritual care. One support team member noted this integration, saying, “That person who is in the emergency room with a pain in their bone from cancer should not be alone. … They need somebody who’s their advocate. … They need somebody to talk them through the experience and to give them meaningful and maybe even prayerful support to get through that pain experience”

**Provision of Emotional and Spiritual Support to Persons With Serious Illness**

In this participant sample, mainly comprised of church-attending African-Americans, spiritual and other emotional aspects of care were viewed as important, yet not available in a cancer center or doctor’s office. The importance of having spiritual needs met and the role of support teams in facilitating spiritual support was voiced by nearly all participants in these interviews. One support team member describes how a support team provides “…encouragement that has
kind of a spiritual overtone overtly…it may be prayer and again that’s not something that people
are typically going to get along the continuum of care from institutions or health care facilities or
at a cancer center or anything like that."

Depression is a common complication of living with chronic or incurable illness. . Recipients of
the Circles of Care support team intervention described feelings of depression and anxiety
related to their cancer illness and how support helped to alleviate their symptoms. Many
descriptions of depressive symptoms in these semi-structured interviews included vernacular
terminology such as feeling down or low; for example, one person with serious illness said,
“Before they started coming, I was down and out…. But since they’ve been coming, it’s done lift
me up. I don’t feel down no more. I just feel good and happy since they’ve been coming. They
lift my spirit up. ”

Another person with serious illness described thoughts about suicide and how support reduced
the severity of depression. She said, “…I have thought about killing myself. I’ve been just down
because the sickness and all, you know, has been bothering me and all that and when they
[support team volunteers] come along and start talking to me, all that left me and now I thank
God for it; none of that don’t cross my mind no more. All I’m doing is looking up towards the
Lord. He’s the only one that can help me to bring me through.”

Recipients of the Circle of Care support team model also expressed other emotional and
spiritual benefits including encouragement, motivation, fostering the will to live, and alleviating
feelings of loneliness. One person with serious illness described the unique role of her support
team member, who is also a cancer survivor, in encouragement and emotional support; “Well
the support team has been there for me to talk more about cancer… because one of my support
members has gone through the same thing and she talks to me…”
Other recipients described the support team as filling emotional needs when family members fell short. One person with advanced illness reflected, “I got a Mother’s Day card from one of them and it was the only Mother’s Day card I received and I do have a child…”

Healthcare providers who participated in the Circles of Care support team intervention also echoed sentiments concerning the importance of emotional and spiritual support. A physician who had referred patients said, “I believe that one of the most important roles that a support team member can play as it pertains to the spiritual life of the friend is to be a sounding board, to be someone who accepts that person’s journey and is able to encourage the friend to tell the story or the stories of his or her spiritual journey and sometimes the language is spiritual or religious and sometimes it’s not but we can learn a lot by asking someone to share his or her story.”

Extension of Support To Families

Recipients of Circles of Care support and support team members both noted that the benefits extended to the children of persons with advanced illness. Support provided to children included support for emotional and practical needs. One person with serious illness noted “… they [support team] help my kids see what I’m going through; I have lung cancer, I was diagnosed with it and they let people know, let my children know that it’s a lot of love around a lot of people.”

Support team members also described providing practical support for the children of persons with serious illness including transportation to shopping centers, recreational activities and personal grooming appointments. One support team member said, “It was very inclusive of the family. Well it kind of took some of the pressure off of them… when your loved one is going through some stuff, it’s stressful. There’s a lot of pressure on the family.”
A pastor, who also served as a caregiver for a family member with cancer, described the potential benefit of the support team providing support for the family by sharing knowledge about things to anticipate in the trajectory of severe illness. “… I can recall as a caregiver for my father-in-law, there were things that my wife and I could not do or had to learn to do and it would have been very beneficial to us to have somebody to come in and help us with, with a lot of the things that we needed to do… we learned by trial and error…”

Several participants also noted that caregiver burnout is a concern in advanced illness that may be address by the support team. For example, one health care provider noted that “…the realities of dealing with an ill person are that it is very draining in terms of time, in terms of emotional investment, in terms of trying to understand the illness and then get proper treatments and interventions … one of the greatest thing about the practical support that our support teams give is that it allows that caregiver to have respite…”

Fulfillment in Service

A final theme described the benefit of fulfillment from serving others that accrued to the volunteer support team members themselves. Participants responded that support team provided benefits to members including a sense of fulfillment, an opportunity to offer Christian service, and serve altruistic motives. A support team member stated, “I just feel so compassionate and so, it’s almost like it’s a healing experience for me to be involved with someone who needs this kind of support. …” Another support team member wondered who benefited the most, saying, “It’s just a really great chance to get to know someone in the community and I honestly think I’m getting more out of it than she is.” Although fewer interview responses addressed benefits to support team members, in comparison to benefits for persons
with advanced illness and their families, the experience of fulfillment in service is described as valuable.

**Perceived Barriers to Participation in Circles of Care**

Persons with serious illness and support team members describe potential barriers to support including the desire of persons with serious illness to *maintain a sense of independence, initiate their own support requests, and maintain a sense of normalcy and privacy*. The limitations of support provided by a volunteer support team were also described as a potential barrier.

**Maintenance of Independence**

Maintaining one’s independence was mentioned by persons with serious illness who accepted support teams and those who declined participation. The tension between a desire for independence and autonomy in the setting of serious illness and an acknowledgment of the need for practical and emotional support was described by respondents. For example, one person with serious illness said, “I don’t think a support team should say this is how we’re going to outline our care for you because that may not necessarily fit with what I want.” Persons with illness also indicated that retaining the autonomy to ask for support when needed and not feeling obligated to accept the help that is offered to them through the support team was an important barrier to participation. One person with advanced illness said, “I don’t envision a support team as being for me, constantly in my space, constantly calling, constantly checking. I don’t think I need that; even though I’m a cancer patient long term, I don’t find I need that as much as maybe another patient.”
Desire for Normalcy

In addition, persons with illness identified a desire for normalcy and a rejection of support on the basis that it signals a loss of hope or vitality. One person with advanced illness, who had accepted a support team for themselves, imagined this acceptance would not be universal, saying “I don’t want you coming into my space because your presence could mean a death sentence. Well I’m to the point where I have to have Circles of Care or other groups like Circles of Care coming in and some patients are not to that point yet. They want to live a normal life.”

Limitations of Volunteer Support

Finally, many stakeholders acknowledged that volunteer support has its limits, and that this may be a barrier to wide acceptance of support teams. Interview participants noted that some persons with illness or support team members may lack understanding regarding the scope of volunteer support teams and what they are capable of providing. Support team members mentioned concerns about the limitations of volunteer support and limited coordination among support team members. Some support team members found it difficult to integrate the demands of volunteering into their daily routine. From the perspective of support team members, there was a perceived lack of training or preparedness to handle the complex medical, emotional, social, and spiritual issues of terminal illness and cancer. One support team member commented, “A social worker or somebody should’ve been in charge of this case so that we had a source with all the information… because part of the time she didn’t know what tests she was going to have, she didn’t know about her meds, she was confused last week even. I took her to Rex or the cancer center over there. She had no idea why we were going”
Discussion

This qualitative evaluation of a community based and faith centered support team intervention for persons with serious illness provides evidence to support its potential benefits. Stakeholder interview responses highlight the ability of support teams to blend practical emotional and spiritual support for persons with serious illness. The benefits of the intervention are endorsed by varied stakeholders, including the perspectives of those who gave or received support. Generally endorsed barriers to participation include balancing asking for help and maintaining independence, gender mismatches between support team volunteers and persons with serious illness, and the limitations of volunteers in dealing with an individual’s complex needs.

Our findings can be compared and contrasted with results of an evaluation of a church-based support group for African Americans with cancer. The support team intervention differed from the support group intervention in that the support team focused on one person with illness, and physically travelled to the location of person with illness. While both interventions provide access to information, emotional and spiritual support, the support team also provides practical support such as transportation.9

The utilization of existing social structures and community partnership were instrumental in the development and implementation of this support team intervention. The socio-ecological theory of community health promotion acknowledges the role of trusted sources within social networks10 and highlights the importance of maintaining a strong community presence in an intervention such as a support team. Peer support may be based in social networks, as when lay health advisors serve their communities, or in health care organizations, through patient navigators.11

The applicability of this program evaluation is limited by heterogeneity within the African-American community, regional variability, and limited male participation in the intervention.
Selected participants from each level of participation within the support team model were interviewed to obtain a well-rounded view of the model and we also recruited individuals who were referred to participate in the model but did not participate in the actual intervention. As support needs are often dynamic in nature, future evaluation of this intervention will include longitudinal analysis of support needs of persons with illness and how this intervention is able to meet those needs. Further studies are needed to evaluate measures of quality of life.

In conclusion, this community based participatory project facilitated the exchange of ideas leading to the development of support teams that were coordinated yet flexible enough to adapt to the needs of individual with illness. The support team model allows volunteers within existing community structures, including churches, to combine efforts and deliver support to those in need. The sense of fulfillment in service among volunteers may be an important motivator in sustaining an intervention based on volunteer support. The implementation of culturally sensitive interventions grounded in the principles of palliative care and social support, such as the Circles of Care intervention, may improve understanding of cancer support needs among African-American patients and their faith communities, and access to practical, emotional and spiritual support during illness.
Table 1: Characteristics of Interview Participants

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<thead>
<tr>
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<th>N</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
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<tr>
<td>Female</td>
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<td>77%</td>
</tr>
<tr>
<td>Male</td>
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<tr>
<td><strong>Age (years)</strong></td>
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<tr>
<td>20-39</td>
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</tr>
<tr>
<td>40-59</td>
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</tr>
<tr>
<td>60-79</td>
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<td>11%</td>
</tr>
<tr>
<td>80-89</td>
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</tr>
<tr>
<td>Age not reported</td>
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<td>36%</td>
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<tr>
<td><strong>Race</strong></td>
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<td>African American</td>
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<td>Caucasian</td>
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<td>Asian</td>
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</tr>
<tr>
<td>Other</td>
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<td>2%</td>
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<tr>
<td><strong>Role of Participant</strong></td>
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<td>Clergy</td>
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<tr>
<td>Person with advanced illness*</td>
<td>10</td>
<td>19%</td>
</tr>
<tr>
<td>Healthcare Provider</td>
<td>6</td>
<td>11%</td>
</tr>
<tr>
<td>Support Team Member</td>
<td>27</td>
<td>52%</td>
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*Two persons with advanced illness did not participate in the support team model but agreed to participate in an interview.
Table 2: Selected themes identified in the semi-structured interviews relating to benefits of the Circles of Care Support Team intervention.

<table>
<thead>
<tr>
<th>Selected Themes</th>
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<tbody>
<tr>
<td><strong>Perceived Benefits of Support Team Model</strong></td>
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<tr>
<td>Consistent coordinated support</td>
<td>Persons with illness, support team members</td>
</tr>
<tr>
<td>Complementary to medical care</td>
<td>Persons with illness, providers</td>
</tr>
<tr>
<td>Emotional and Spiritual support to Persons with serious illness</td>
<td>Persons with illness, clergy, caregivers, providers</td>
</tr>
<tr>
<td>Extension of support to the family of persons with illness</td>
<td>Support team members, clergy, persons with illness, providers</td>
</tr>
<tr>
<td>Sense of fulfillment, Christian service, altruism</td>
<td>Support team members</td>
</tr>
<tr>
<td><strong>Perceived Barriers to the Support Team Model</strong></td>
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<tr>
<td>Maintenance of independence</td>
<td>Persons with illness</td>
</tr>
<tr>
<td>Desire for Normalcy</td>
<td>Persons with illness</td>
</tr>
<tr>
<td>Limitations of Volunteer Support</td>
<td>Support team members</td>
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</tbody>
</table>
References


Appendix A: Review of literature pertaining to psychosocial support needs of African-Americans living with cancer

Persons living with cancer and other serious illness may have support needs not traditionally met by the health care system, including practical, social, emotional and spiritual support. There is a growing body of both qualitative and quantitative literature which addresses the identification of these support needs among diverse populations including minorities and the underserved. Much of the existing research focuses on survivorship and the physiologic, psychosocial, and economic sequelae of cancer and its treatment; whereas palliative care literature in this subject area continues to expand. A literature search was performed the MeSH terms, social support, cancer, and African Americans using data sources including MEDLINE® searches from 1990–present were conducted to locate articles about cancer support needs among minority and underserved populations. Four hundred and sixty-eight articles were found and underwent abstract review for content regarding practical, social, emotional, and spiritual support needs; forty-four articles were identified and underwent full text review; twenty-two articles were excluded due to emphasis on other topics such as medical management, self-help groups, or testing/evaluation of a specific research methodology. The results of this literature review suggest that more research is needed to identify the social support needs of minority populations with cancer and the preferred method of receiving help among such populations. Acknowledgement and identification of these support needs is necessary to inform the design of interventions to provide support services to these populations.

A 2007 study conducted in New York City surveyed a total of 248 oncology outpatients (48% non-Hispanic whites, 25% African Americans; 19% Hispanic) and identified four main areas of support needs: informational, practical, supportive, and spiritual. Ethnicity was the sole predictor of needs (P <.02), even after controlling for education, time since diagnosis, treatment status, marital status, and age. The mean percentage of needs endorsed by African Americans,
Hispanics, and non-Hispanic whites respectively was 81%, 85%, 70% for informational; 63%, 68%, 36% for practical; 69%, 73%, 48% for supportive; and 49%, 60%, 31% for spiritual needs.\(^1\)

A subsequent study in 2011 by Mosavel and Sanders also aimed to identify the needs of low income, African American cancer survivors in an urban setting. Qualitative data were collected from semi-structured interviews conducted with cancer survivors (n=12), caregivers (n=10), professionals (n=10), and surveys from town hall meetings (n=80).\(^2\) Participants from all groups identified practical needs including transportation, financial and job assistance, childcare and self-care assistance.\(^2\) In addition, cancer survivors and caregivers desired more education and lifestyle information upon diagnosis as well as afterwards, including a better post-treatment plan, and more need for social support. Participants also identified the ideal resource center as being located within the survivor’s neighborhood which hypothetically could provide a range of medically specific support and recreation.\(^2\) Participants suggested that needs for cancer survivors are complex due to culture, family structure, and financial limitations.\(^2\)

Other studies have also elucidated the need for more health-related and cancer-specific education, the importance of faith and spirituality, and the availability of support. Persons with cancer also may have difficulty identifying and articulating financial needs.\(^3\) Few participants report requesting or receiving assistance (financial or otherwise) outside of their own family during their cancer experience. Treatment-related medication costs posed a significant hardship for many.\(^3\)

Personal care and home activity needs were reported as not being adequately addressed in a sample (n=63) of low-income, urban-dwelling, black patients with cancer.\(^4\) Practical support needs were not the only needs identified, as some participants had unmet medical concerns including symptom management. Women who were elderly, black, alone, poor, and chronically ill were likely to have unmet needs and high levels of symptom distress including nausea, pain, and dyspnea.\(^4\)
The informational needs of cancer patients may change over time and may be associated with educational attainment and not necessarily depend on health literacy levels \(^{5,6}\). A 2003 analysis of over 19,000 patient calls made to the National Cancer Institute’s Cancer Information Service Hotline revealed differences in main topics of interest for patients based on demographic characteristics and stage along the cancer care continuum.\(^5\) Females were more likely than males to inquire about cancer screening, diagnosis, support services, psychosocial issues, and general cancer site information, but they were less likely to seek specific cancer treatment information.\(^5\) Compared with white callers, hispanics and black callers were more likely to seek support service information, and blacks were more likely to have questions related to psychosocial issues. Compared with patients in treatment, patients in recurrence were more likely to seek specific treatment information; patients not in treatment were more likely to seek medical referral information; and patients in post-treatment were more likely to seek screening, diagnosis, prevention, and risk factor information.\(^5\)

The presence of low health literacy has been shown to be higher among minority populations and the underserved. Cancer patients and their families often make complex decisions regarding procedures and therapies. Informed decision-making requires access to, the ability to process, and to understand cancer-related information. Individuals with limited health literacy may not be able to obtain or understand important information about their cancer and treatment.\(^6\) Matsuyama and colleagues examined the associations between race, health literacy, and self-reported needs for information about cancer related issues, physical care, and psychosocial resources among 138 newly diagnosed cancer patients. Their findings suggest that educational attainment, rather than health literacy, may be a significant predictor of information needs.\(^6\)

The social support needs of African American women with breast cancer have been described in qualitative studies. A 2007 study by Shelby et al. examined the perspectives of 77 African American women treated for non-metastatic breast cancer.\(^7\) Social support was found to
buffer the negative impact of low optimism on psychological distress, well-being, and psychosocial functioning. Women with high levels of social support experienced better adjustment to their cancer treatment even when their optimism was low. Optimism and social support are associated with better adjustment following breast cancer treatment. Women who report more satisfaction with their social support networks had greater functional wellbeing and social and family well-being. A study examining the psychosocial concerns of young African American breast cancer survivors (n=33), described by Lewis et al., found that nearly one-third of participants desired additional emotional support at and after diagnosis and believed their breast cancer treatment interfered with employment. In addition, nearly half of women felt cancer negatively influenced romantic relationships. A large percentage (45%) wanted children at diagnosis, but only half of these women ever received fertility information. One third reported sexual problems, but 73% never discussed sexuality with providers. Fifty-two percent lacked information about cancer-related sexual dysfunction. Lewis' and colleagues conclude that the spirituality of African American women may facilitate cancer adjustment, but cultural taboos surrounding women's health issues may interfere with obtaining information necessary for developing successful coping strategies.

Coping strategies for individuals with cancer encompass a variety of dimensions including spirituality and the maintenance of existing personal relationships. Distinct coping profiles of older African Americans with cancer were identified in a study by Hamilton and colleagues. Four hundred and forty nine individuals were surveyed using the Ways of Helping Questionnaire. Coping profiles were associated with participant’s gender, age, and whether the participant lived alone. Coping profiles were also associated with religiosity; experiences with racism; and physical, psychological, and relationship well-being. Elements of coping profiles included whether participants “felt that others were there for them”, had their “physical and treatment care needs met”, “sought help from God and the church”, or had a
strong presence of family support. Other elements of coping strategies involved whether participants felt they were “still able to help others” or able to “be strong for others” in their existing relationships. Distraction from the disease process itself was also reported as an essential coping strategy for some participants.\textsuperscript{15,16}

A qualitative study of 23 rural and urban African American prostate cancer survivors found that family and physician support were important for coping with cancer; the participants’ wife was cited as the most important and consistent source of support.\textsuperscript{17} Participants also relayed that health insurance is viewed as a necessity for receiving appropriate health care and decreases anxiety and financial hardship. Rural prostate cancer survivors found that spirituality was more important during diagnosis and treatment of their prostate cancer.\textsuperscript{17} When a predominantly rural African-American sample of cancer survivors was surveyed about coping techniques, the preferred stress-management topics listed were humor therapy, music therapy, meditation, and relaxation; lower-ranked topics included pet therapy and art as therapy.\textsuperscript{18}

Guidry and colleagues examined the role of informal and formal social support networks in reducing barriers to cancer treatment among a diverse sample of 593 patients.\textsuperscript{19} Social support networks were found to be valuable in assisting cancer patients with continuation of treatment, especially in black and Hispanic participants. However, fewer than half of the respondents report that they were asked by a healthcare professional whether they would be interested in joining a formal social support group at the time of diagnosis.\textsuperscript{19} Individuals of all racial/ethnic groups reported that the formal support groups provided emotional assistance. In addition, informal social support networks, such as extended families and civic clubs, were seen as more helpful for blacks and Hispanics as compared with whites.\textsuperscript{19} Guidry and colleagues conclude these networks should be acknowledged by healthcare professionals as they are an important part of coping strategies and cancer supportive care.

African Americans are thought to have lower participation rates in formal support mechanisms than their white counterparts\textsuperscript{20}, although the data are mixed regarding this
question. A recent study of breast cancer patients in North Carolina (n=958, 26% African American sample), found no racial difference in support group participation. However, recruitment challenges for support group participation among minority women with breast cancer have also been cited. In a planned collaborative research effort with lay community leaders, recruitment of women into a support group intervention remained low despite an expressed need from that particular community to increase education and support surrounding breast cancer diagnosis and treatment. African-American cancer survivors may also be underrepresented in online cancer support groups; mechanisms that could perpetuate this imbalance include differences in computer skills, higher preferences for face-to-face support or culture-specific online support, and concerns regarding online privacy. Strategies to include cultural relevance in psychosocial interventions targeting African American cancer patients have focused more on enhancing recruitment and retention and less on the inclusion of sociocultural concepts into the content of the intervention.

In summary, the review of a large portion of the existing literature on social support needs of African Americans with cancer revealed a number of qualitative and cross-sectional studies. Examining a phenomenon such as social support within a subgroup of minority patients is difficult to research and may not be generalizable across geographic regions, religious preferences, economic status and education. African Americans are not a homogeneous group; however, identifying commonly unmet supportive care needs in this population is of great importance considering the known disparities in cancer diagnosis and outcomes within this group.


Appendix B: Qualitative Methods

Our study, a qualitative analysis of participant perspectives from the Circles of Care Support Team intervention, is based upon the qualitative method of grounded theory with the inclusion of some elements of phenomenology theory. Grounded theory analysis methods seek to develop an explanatory theory of social processes, e.g. psychosocial support needs in cancer care. Phenomenology uses individual experiences to capture the meaning and common features, or essences, of an experience or event.¹

Purposive sampling methods were used to recruit participants who have experienced cancer or other serious illness and participated in the support team intervention; this type of sampling is common in both phenomenology and grounded theory methods. The concept or the experience under study is the unit of analysis; given that an individual person can generate hundreds or thousands of concepts, large samples are not necessarily needed to generate rich data sets.² Grounded theory relies on theoretical sampling, which involves recruiting participants with differing experiences of the phenomenon in order to explore multiple dimensions of the social processes under study.² In this study, participants from multiple roles were recruited including persons with illness, caregivers, clergy, health care providers and support team volunteers. The study coordinators continued to add individuals to the sample until theoretical saturation was reached and the complete range of perspectives was fully represented by the data. Typical grounded theory studies report sample sizes ranging from 10 to 60 persons.²

Grounded theory begins with general research questions rather than adhering firmly to pre-conceived hypotheses. The rigor of the grounded theory method depends upon developing the range of relevant conceptual categories, providing repeated evidence for those categories, and explaining the data. Similar to quantitative studies, or any other research, the quality of
grounded theory studies varies according to the methodological thoroughness, the significance of the research questions, and the inclusiveness of the analysis. Grounded theory methodology also involves reviewing the literature later in the research process as a strategy to encourage the exploration of various ways of analyzing the data. Delaying the literature review is thought to decrease the likelihood that the researcher will already be locked into preconceived hypotheses upon gathering the interview data and in interpreting the data.

In contrast to other qualitative research methods, grounded theory minimizes validating the 'accuracy' of a specific piece of data and instead emphasizes its theoretical relevance. For example, two people, such as a person with illness and his/her caregiver, may give different accounts of the person with illness' activities. The analytic issues raised within each view take precedence over determining which perspective of reality comes closer to 'truth'.

The analysis of qualitative interview data is an iterative, inductive process of de-contextualization and re-contextualization. During de-contextualization the analyst separates data from the original context of individual cases and assigns codes to units of meaning in the texts. In re-contextualization the codes are re-examined for patterns and then reintegrated, organized, and reduced around central themes and relationships drawn across all the cases and narratives. In our study, we developed fifteen codes from the narrative data including those defined below.
<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Barriers to Support Team Model</td>
<td>Actual or potential situations or issues that might challenge the development or sustainability of the Support Team intervention. Includes things that may keep persons with illness from accepting a team. Also includes specific examples of challenges to existing Support Teams.</td>
</tr>
<tr>
<td>Sub-codes:</td>
<td></td>
</tr>
<tr>
<td>- Expectations</td>
<td></td>
</tr>
<tr>
<td>- Friend Perceptions</td>
<td></td>
</tr>
<tr>
<td>- Gender</td>
<td></td>
</tr>
<tr>
<td>- Integrating Circles of Care</td>
<td></td>
</tr>
<tr>
<td>- Lack of Communication/Coordination</td>
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<tr>
<td>- Lack of Knowledge of Circles of Care</td>
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<tr>
<td>- Lack of Understanding of Circles of Care</td>
<td></td>
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<tr>
<td>- Maintaining Independence</td>
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<tr>
<td>- Team Member Perceptions</td>
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<tr>
<td>2. Benefits to Family of Friend (Person with illness)</td>
<td>Describes how the support team experience has or could benefit the person with illness. Quotes may also include mutual benefit to family and support team and be double coded.</td>
</tr>
<tr>
<td>3. Benefits to Friend</td>
<td>Examples of how the support team has or could benefit the Friend.</td>
</tr>
<tr>
<td>4. Benefits to Support Team Members/Community</td>
<td>Actual or potential reward to support team members from their interactions with the Friend or other support team members.</td>
</tr>
<tr>
<td>5. Call to Service</td>
<td>Examples of this code include a participants’ description of his/her own Circles of Care volunteer experience as a “calling” or passion for service or helping improve the lives of others.</td>
</tr>
<tr>
<td>6. Cancer (Illness)Journey</td>
<td>Examples of this code include a participant’s description of his/her own cancer (or other illness); experience/journey with the cancer; the experience/journey of others</td>
</tr>
<tr>
<td>7. Connection</td>
<td>Includes when an actual person with illness or support team volunteer describes how the connection was made in bringing the person and support team volunteers together- the actual steps, strategies etc that took place-“the story” of how it all happened.</td>
</tr>
<tr>
<td>8. Gaps-Additional Needs</td>
<td>Any mention of services or resources needed in the community and/or those services, resources or types of assistance not currently being met by Circles of Care or other organizations. Also any mention of lack of awareness about existing services and resources.</td>
</tr>
<tr>
<td>9. Facilitators to Support Team Model</td>
<td>Actual or potential characteristics or examples of things that must be in place in order for a support team to function successfully.</td>
</tr>
<tr>
<td>Communication/Coordination</td>
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<tr>
<td>Expectations</td>
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<td>Friend Perceptions</td>
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<td>Gender</td>
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<tr>
<td>Code</td>
<td>Description</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>10.</td>
<td>Other Non-Circles of Care support received</td>
</tr>
<tr>
<td>11.</td>
<td>Recruitment Message</td>
</tr>
<tr>
<td>12.</td>
<td>Support Team Care Supplements Medical Care</td>
</tr>
<tr>
<td>13.</td>
<td>Support Team Defined</td>
</tr>
<tr>
<td>14.</td>
<td>Training Feedback</td>
</tr>
<tr>
<td>15.</td>
<td>Unique Qualities of Support Team</td>
</tr>
</tbody>
</table>

A specific code is less abstract than a conceptual category. A conceptual category, which we incorporated into memo-writing, is part of a larger theoretical framework. When treating a term as a conceptual category, we specify its properties, note the conditions under which it arises, relate how it changes, describe its consequences, and specify its relationship to the other conceptual categories.¹ We compiled descriptions of ideas and categories into organized “memos”, where we defined what is implicit and what is explicit in the data. Memo-
writing provides an analytic focus on the materials and a means of discovering and defining hidden or taken-for-granted processes and assumptions within the data. Memos were created for each of the above mentioned codes; from each memo draft, conceptual categories were also developed during the analysis. For example, within the construction of the memo for barriers to participation, several conceptual categories were identified such as: (1) living, not dying / desire for normalcy, (2) certain supportive behavior doesn’t come naturally for men, (3) not all volunteers are equal, and (4) limits of volunteer support / need for professional care. These conceptual categorizations helped to further identify associations within the data that could be used in our analysis. Using selected principles of grounded theory methodology facilitated a description of theories and perspectives associated with the social process of emotional, spiritual and psychosocial support needs of persons with cancer and other serious illnesses.

References


Appendix C: Circles of Care Support Team Interview Questions

1. What has the Support Team meant to you and your family?

2. How is the Support Team different from getting help at a Cancer Center or doctor’s office?

Second, I’d like to ask you about different ways a Support Team might work with you and your family. I’m curious whether you see this as something people need when facing cancer, and this might be a way Support Teams can help other African Americans with cancer.

3. Do people facing advanced cancer need PRACTICAL SUPPORT – for example, help with transportation, meals, errands, household tasks, or yard work? Is this something Support Teams can do? (Probe: If yes, how has this been helpful to your family? How do you think this type of support would be helpful to others?)

4. Do people facing advanced cancer need EMOTIONAL AND SOCIAL SUPPORT – for example – visits, calls, e-mails or notes, or just staying with you through a hard time? Is this something Support Teams can do? (Probe: If yes, how has this been helpful to your family? How do you think this type of support would be helpful to others?)

5. Do people facing advanced cancer need SPIRITUAL SUPPORT – for example – prayer, communion, spiritual conversation, fellowship, help getting to worship or meetings, or even spiritual support for your family? Is this something Support Teams can do? (Probe: If yes, how has this been helpful to your family? How do you think this type of support would be helpful to others?)

6. Do people facing advanced cancer need QUALITY OF LIFE SUPPORT – for example – social outings, help with hobbies, help with pets, or other things that improve your quality of life?
Is this something Support Teams can do? (Probe: If yes, how has this been helpful to your family? How do you think this type of support would be helpful to others?)

7. Do people facing advanced cancer need ADVOCACY AND RESOURCE SUPPORT – for example – tapping into community resources, problem-solving, organizing records or bills? Is this something Support Teams can do? (Probe: If yes, how has this been helpful to your family? How do you think this type of support would be helpful to others?)

8. Do people living with advanced cancer need CANCER SPECIFIC SUPPORT – for example – encouraging communication with health care providers, going to doctor visits or treatments, finding cancer information, finding support groups, getting help with pain management, or helping with hard decisions? Is this something Support Teams can do? (Probe: If yes, how has this been helpful to your family? How do you think this type of support would be helpful to others?)

9. Did you receive or need one type of support more than the others? Were there other types of support you needed that were beyond what a support team could provide?

10. Are there things you would have changed about the support team experience?

11. How would you describe your overall support team experience?
What is the Purpose of this Study?

- To describe the perspectives of participants (N=47) in a community and church-based support team program providing practical, emotional and spiritual care for persons with cancer and other advanced illness within the African-American community.

What is the Problem?

- Persons with serious or chronic illnesses often have great need for supportive care, including practical, emotional and spiritual care.
- Active social and spiritual support for persons with cancer and other serious illnesses has been shown to improve psychological adjustment to illness and improve quality of life.
- The need for support may be increased by disparities in health and poor access to healthcare, such as those experienced by African-Americans with cancer and other serious illnesses.
- African-Americans may recognize more spiritual needs in relationship to cancer supportive care.

What are the Findings?

- Participants in the support team program report multiple benefits to participation including receiving consistent support, support complementary to medical care, as well
as emotional and spiritual support. Other benefits included an extension of support to patients’ family members, and the fulfillment of service.

- Reported barriers to participation in the support team included a desire for a normal life, independence, and to initiate one’s own support needs.
- Support team volunteers reported perceived weaknesses in volunteer support and scope of training.

Who Should Care Most?

- Community and church based organizations interested in providing support to persons with illness
- Caregivers, clergy, counselors, and physicians serving persons with illness
- Academic departments interested in forming community partnerships to address disparities in supportive care

Recommendation for Action

- Provide ongoing community education and support to maintain a framework for support team formation and training.
- Increase awareness within churches and other community organizations about the support needs of persons with serious illness and how existing resources can be used to meet those needs.
- Increase awareness among medical providers of how the practical and spiritual support needs of their patients can affect participation in medical care.