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Circles of Care: Development and Initial Evaluation of a Peer Support Model for African Americans With Advanced Cancer

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Abstract

Peer support interventions extend care and health information to underserved populations yet rarely address serious illness. Investigators from a well-defined academic–community partnership developed and evaluated a peer support intervention for African Americans facing advanced cancer. Evaluation methods used the Reach, Efficacy, Adoption, Implementation, Maintenance (RE-AIM) framework. Investigators initially recruited and trained 24 lay health advisors who shared information or support with 210 individuals. However, lay advisors reported barriers of medical privacy and lack of confidence working alone with people with cancer. Training was modified to match the support team model for peer support; training reached 193 volunteers, 104 of whom formed support teams for 47 persons with serious illness. Support teams were adopted by 23 community organizations, including 11 African American churches. Volunteers in teams felt prepared to implement many aspects of supportive care such as practical support (32%) or help with cancer or palliative care resources (43%). People with serious illness requested help with practical, emotional, spiritual, and quality of life needs; however, they rarely wanted advocacy (3%) or cancer or palliative care resources (5%) from support teams. Volunteers had difficulty limiting outreach to people with advanced cancer due to medical privacy concerns and awareness that others could benefit. Support teams are a promising model of peer support for African Americans facing advanced cancer and serious illness, with reach, adoption, and implementation superior to the lay advisor model. This formative initial evaluation provides evidence for feasibility and acceptance. Further research should examine the efficacy and potential for maintenance of this intervention.

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Declaration of Conflicting Interests

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Keywords

African American; community-based participatory research; evaluation; formative evaluation; health behavior; lay health workers; race/ethnicity

Health care disparities continue to limit quality cancer care (Freeman & Payne, 2000; Smedley, Stith, & Nelson, 2002). African Americans receive less timely cancer screening and less effective treatment of early stage disease (Bach, Cramer, Warren, & Begg, 1999; Carey et al., 2006; Peek & Han, 2004; Shavers et al., 2004). As a result, they are more likely to experience advanced, incurable cancer (Cykert et al., 2010; Howlader et al., 2011). Patients facing advanced cancer need effective treatment for pain, communication about treatment options, and supportive care (Peppercorn et al., 2011). Advance care planning empowers patients to control the type of treatment they receive, but African Americans are less likely to create advance directives. Providers less often communicate with African American patients about treatment preferences, and patients are less satisfied with the quality of communication (Haas et al., 1993; Hanson & Rodgman, 1996; Welch, Teno, & Mor, 2005). Compared with patients of European descent, African American cancer patients experience less effective pain management and less hospice access (Anderson et al., 2000; Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997; National Hospice and Palliative Care Organization, 2011; Smith, Earle, & McCarthy, 2009).

In contrast with cancer prevention and early treatment, few public health interventions have been designed to address disparities in advanced cancer. Peer support interventions promote health care for underserved populations by providing information, advocacy, and practical, emotional, and spiritual support (Fisher, Earp, Maman, & Zolotor, 2010). These interventions are based on the socioecological theory of community health promotion, which acknowledges the important role of trusted sources within social networks (Golden & Earp, 2012; McLeroy, Bibeau, Steckler, & Glanz, 1988). People who provide peer support are “natural helpers”—individuals whose skills and compassion may be enhanced by training (University of Arizona & Annie E. Casey Foundation, 1998). Peer support may be based in social networks, as when lay health advisors serve their communities, or in health care organizations, through patient navigators (Freeman, 2006). Lay health advisors are effective to improve physical activity, nutrition, smoking cessation, immunizations, breastfeeding, infectious disease treatment, and cancer screening (Earp et al., 2002; Golden & Earp, 2012; Lewin et al., 2005; Webel, Okonsky, Trompeta, & Holzemer, 2010). Navigators increase cancer screening follow-up and early cancer treatment for underserved populations (Percac-Lima et al., 2009; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010).

The support team model is a form of peer support uniquely adapted to the needs of people with serious illness. Members of support teams work together to provide practical, emotional, and spiritual support, by doing “what you can, when you can, in a coordinated way, with a built in support system” (Project Compassion, 2010). The model began with the Support Team Network created to enhance community-based HIV care at University of Alabama in 1994, and has been cited by AARP, the Robert Wood Johnson Foundation, National Council on Aging, Metlife Foundation, National Hospice and Palliative Care

Organization, and the Lance Armstrong Foundation. However, this model has not been evaluated; only one published study provides preliminary description of the support team model for Alzheimer's patients (Stevens, Lancer, Smith, Allen, & McGhee, 2009).

Peer support interventions have addressed health promotion and prevention; this study is the first to examine whether peer support can help people living with persistent and serious illness. Academic experts and community partners collaborated to achieve the objectives of this study, which were (a) to develop a model of peer support for African Americans facing advanced cancer and (b) to evaluate and compare the lay health advisor and support team models.

Method

Research Partnership

The research partnership used a community-based participatory research approach to combine the expertise of academics, clinicians, and community advocates. Research was conducted in a three-county area of central North Carolina from July 2005 to July 2010. Investigators had expertise in patient advocacy, health ministry, spirituality and health, oncology, and palliative care. Participating health care organizations included an NCI-designated Comprehensive Cancer Center and a Comprehensive Community Cancer Center of the American College of Surgeons. Participating community organizations were the Community Health Coalition, a health education and advocacy organization addressing health disparities; Healing with CAARE, Inc., a free clinic and health education center; and Project Compassion, a nonprofit organization with expertise in support team training. A 32-member community advisory board with representation from community health advocacy, ministry, and public health service delivery provided guidance.

Development of Peer Support Training: Lay Health Advisors

Implementation of this peer support model was based on the socioecological theory of community health promotion using existing social networks (Golden & Earp, 2012; McLeroy, Bibeau, Steckler, & Glanz, 1988). Lay health advisors were recruited through African American church leaders and health ministries. Recruited individuals were asked to invite others whom they regarded as natural helpers. Publicity materials were included in church bulletins and in news media reaching the African American community. To be included in training, participants had to complete a short application describing personal attributes, spiritual gifts, and prior experience with serious illness and provide three references who endorsed their fitness for the lay health advisor role. They were also asked to describe challenges they anticipated in working with people with serious illness.

Investigators delivered a day-long training, offered several times. Participants practiced approaches for communicating with, advising, and supporting persons who faced serious illness, including sensitivity to confidentiality and boundaries of peer support. Lay health advisors then met monthly for 1 year to share their outreach experiences, discuss barriers, and suggest ways to improve peer support. They also participated in discussions with hospice providers, cancer support group leaders, and supportive care professionals.

Development of Circles of Care Support Teams

Investigators reviewed the evaluation of the lay health advisor model and then modified methods to create volunteer support teams called Circles of Care. Recruitment was similar, but messaging promoted the concept of teamwork. For example, a training flyer stated “Using a team approach, community volunteers pool their talents, creativity, and time to offer more support than individuals can provide.” Training content included information on how to build and sustain a team. Curriculum was original to this study and included information on peer support through emotional and spiritual caregiving, awareness of health disparities in cancer care, and information on community resources in pain treatment, palliative care, hospice, and cancer care (Table 1).

New volunteers, separate from those who trained as lay health advisors, were recruited from community organizations or the social network of an individual with cancer. Volunteers elected a 3-hour team member training or a day-long team leader training that prepared individuals to create and lead a team within their church or community. Support teams included 6 to 10 trained volunteers who agreed to work together to support one or more individuals with advanced cancer, called “support team friends.” Individuals with cancer in need of support were identified in two ways—referral to the Circles of Care project from cancer center clinics or referral from the churches and community connections of the trained support team volunteers.

Evaluation Methods

The evaluation used portions of the Reach, Efficacy, Adoption, Implementation, Maintenance (RE-AIM) framework for public health interventions; given the early phase of this research, efficacy and maintenance were not tested (Glasgow, Vogt, & Boles, 1999). This widely accepted framework is used to measure public health impact. To evaluate the lay health advisor phase of the study, investigators examined the *reach* and *implementation* of lay health advisor peer support over a 1-year period. Reach was defined as the number of lay health advisors who completed training and participated in at least one follow-up activity, such as sharing information with a specific person in need or a relevant group such as a cancer support ministry. To understand implementation, health advisors completed an anonymous three-item survey at the end of the study on (a) how many people they supported, (b) where they found these individuals, and (c) what type of information or support they provided to them. The 24 health advisors were also asked to recruit a total of 60 individuals to whom they provided support for a brief interview about implementation.

In the second phase of the study, investigators evaluated the *reach*, *adoption*, and *implementation* of peer support using Circles of Care support teams. Reach was measured as the numbers and characteristics of support team members trained and engaged in support and the numbers of individual they supported. To describe adoption, investigators recorded the numbers and types of recruitment contacts with organizations (churches, clinics, cancer support groups) and frequency with which each type of organization yielded study participants. To evaluate implementation, investigators used parallel written surveys for support team members offering support and persons with serious illness seeking support. In addition to demographic items, the survey listed six categories of support—practical,

emotional, spiritual, quality of life, advocacy, and cancer/palliative care resources. Each type of support was represented by a list of four to eight specific items describing a supportive activity; for example, practical support included transportation, respite, meals, errands, household tasks, whereas spiritual support included prayer, communion, spiritual conversation, or help getting to worship. Each category allowed the individual with serious illness to specify their own needs. For each item, support team members reported whether they felt willing to offer that type of support. People facing serious illness indicated whether or not they desired each specific type of support. All data were analyzed as simple frequencies.

Study procedures were approved by the institutional review board for the University of North Carolina Schools of Nursing and Public Health. All providers of peer support—lay health advisors or support team members—and people with serious illness they supported gave informed consent prior to their participation in evaluation interviews and surveys.

Results

Training Lay Health Advisors to Provide Peer Support in Advanced Cancer Care

Twenty-five volunteers completed training as lay health advisors; all participants were African American women. One participant withdrew following initial training; 24 participants took part in at least one follow-up activity and the evaluation. Participants represented 20 churches, and all successful recruitment used direct, interpersonal methods with extensive information shared prior to commitment to training. All participants were African American women who expressed confidence that they were able to provide the type of support needed in serious illness, and all had prior experience. Two were cancer survivors and three had health care professional training or work experience.

Reach and Implementation of Lay Health Advisor Peer Support

The 24 health advisors shared information and support with 210 individuals during the following year. Spiritual or practical caregiving (52 individuals) and information on community cancer resources (28 individuals) were the most common forms of support. Advisors reported sharing information about pain resources (17 individuals) or hospice and palliative care (11 individuals) less often. Outreach settings included churches, workplaces, medical offices, and voluntary organizations. Health advisors were able to recruit only 10 persons with serious illness (8 with cancer) to be interviewed for the evaluation, so this component of the intervention was omitted.

Barriers to Use of Lay Health Advisors

The evaluation revealed important barriers to the lay health advisor model for support of those with serious illness. Even in their applications, volunteers anticipated challenges—inadequate knowledge of cancer treatment, fear of being with someone who might die, concern about the required time commitment, difficulty controlling emotions, uncertainty about how to address patient–family conflicts, and a need to set limits when patients' needs exceeded the volunteers' ability to respond.

They reported barriers to their effectiveness supporting people with advanced cancer during follow-up meetings. First, they reported that respect for privacy limited their ability to identify and approach people with cancer. People did not easily share their diagnosis of cancer and often did not understand cancer stage. A related concern was difficulty limiting their support to persons with cancer when people with many other illnesses could benefit. Second, they felt conflicted over the advocacy and service motivations that drew them to training and the research objective to recruit people with serious illness to participate in evaluation interviews. Finally, despite their training, some of the lay health advisors expressed a lack of confidence in their ability to meet the overwhelming needs of people with serious illness.

Reach of Circles of Care Support Teams

In response to these results, investigators and community partners modified the peer support approach to train Circles of Care support teams. A total of 193 additional volunteers completed training. Volunteers had a wide age range, 81% were women, and 65% African American (Table 2). Of the 193 volunteers trained, 104 (54%) became active support team participants as leaders (15) or team members (89; Figure 1). Support teams received 115 referrals of African Americans facing serious illness. Direct support was provided to 47 individuals, or 41% of those referred; 41 received ongoing support teams and 6 received information and referral to community resources. Nearly all patients with support teams were African American; 40% had cancer, 57% had non-cancer diagnoses, and one person did not wish to disclose his/her underlying illness.

Adoption of Circles of Care Support Teams by Community Organizations

Circles of Care peer support was adopted by diverse organizations (Figure 2). In total, 88 organizations—16 cancer groups, 34 predominantly African American churches, and 38 other community service organizations such as chapters of African American fraternities and sororities or local health student service clubs—received 240 in-person recruitment contacts. Support team members were more often identified through churches than through any other type of organization; 11 churches, 3 cancer support organizations, and 9 other community organizations actively participated.

Implementation of Circles of Care Support Teams

Evaluation surveys were completed by 79% of persons with serious illness receiving support (37 of 47 eligible) and by 76% of trained support team members (147 of 193 completing training). After completing peer support training, a high percentage of support team members felt prepared to offer different types of supportive care, ranging from 32% who felt prepared to offer practical support to 43% who were able to offer cancer and palliative care specific support (Figure 3). People with serious illness most commonly requested practical, emotional, spiritual, and quality of life support. In the category of practical support, people with serious illness most often requested help with meals, errands, or household tasks. In the category of emotional support, they most often desired supportive visits, calls, and shared time together. Fellowship and prayer were the most frequently requested forms of spiritual support. Under the category of quality of life support, help continuing hobbies and help getting to activities outside the home were the most common needs.

For a few types of support, survey results found discordance between the support desired by people with serious illness and what support team members felt prepared to offer. One third of trained support team members were willing to provide respite care in the home, yet only one person with serious illness requested this help. Few persons with serious illness wanted help with advocacy activities (3%), such as reaching out to community resources or being accompanied to physician visits. Although support team members felt prepared to assist with cancer or palliative care resources, few persons with serious illness requested any related support (5%), when offered help finding cancer information, cancer support groups, information on pain management, or palliative care (Figure 3).

Discussion

This community-based participatory research project, conducted in two phases over a 5-year period, demonstrates the feasibility and initial impact of peer support for African Americans facing advanced cancer and other serious illness. The creation of Circles of Care peer support teams required an effective research partnership between comprehensive cancer care, palliative care, university faculty, and African American churches and advocacy organizations. Peer support is feasible for people with advanced stage illness using the support team model.

Our findings have implications for future research on peer support interventions. First, we found the support team model more feasible than the lay health advisor model for persons with serious illness. Lay health advisors are capable of advocating for specific health behaviors such as getting a cancer screening test. However, the complex needs of people living with advanced cancer and other serious illness may require a team approach. Lay health advisors were initially confident in their training, but found they could not always feel adequate to meet the needs of serious illness. Second, direct and interpersonal recruitment were more effective than broad public invitations. Fewer than 50% of people expressing initial interest were able to make a commitment to participation, so recruitment required significant investment of time and energy. Third, privacy is a strong community value, and referrals to peer support from the cancer center—as used in Circles of Care—may improve access to this type of care. Finally, peer support interventions should be designed to address the tension between community service aims and research aims; evaluation interviews were not well accepted when requested by peer support volunteers, but achieved very good response rates when requested by investigators. This approach allowed peer support providers to focus on service, not research, and kept roles clear to care recipients as well.

In this project, African American churches and community organizations were more likely to adopt the support team model than other organizations. Churches are the most consistently influential organization in the African American community. In a 1997 Gallup poll, 92% of African Americans were religiously affiliated, and 71% attended Protestant congregations (Taylor, Chatters, & Levin, 2003). Collaborative interventions with churches have helped overcome African American health disparities in nutrition, screening, and chronic disease management (Ammerman et al., 2002; Lasater, Carleton, & Wells, 1991; Thomas, Quinn, Billingsley, & Caldwell, 1994). Cancer patients' needs for dignity, understanding the meaning of illness, and seeking comfort in the face of death may be

particularly suited to traditional missions of African American churches. However, reliance on churches alone may limit opportunity for some people in need of support who are not active in a congregation.

Study Limitations

This research is innovative and represents one of the first efforts to create an intervention addressing cancer health disparities among patients with late-stage illness. However, the research is exploratory, and limitations should be acknowledged. First, although the study design and training focused on cancer support, patient privacy barriers in the community made limiting peer support nearly impossible as people did not always reveal their diagnosis or cancer stage. In addition, many volunteers rejected limiting the support team model to cancer. Although the marked needs of cancer patients were clear to them, volunteer teams also saw the relevance of their support to people with other types of serious illness. In the spirit of community-based participatory research, investigators modified the protocol in response to these concerns. To reach persons with serious illness, peer support has to work in partnership with health care providers; this partnership may need to negotiate the differences between health care disease-specific silos and the community perspective on who is most in need. Second, our data show the reach, adoption, and implementation of this model; however, data on efficacy and maintenance of the model, ideally tested against a control condition, is needed before its potential is confirmed. Peer support relationships, built on practical, emotional, and spiritual caregiving, may or may not permit sharing of palliative and supportive care information in a trusting relationship. Third, this intervention is regional in scope. Future studies are required to test whether the model can be exported to other communities and other cancer centers. Finally, peer support, like other forms of supportive care or community outreach, is voluntary and will not be accepted by all individuals facing serious illness with cancer. Although peer support is typically extended to underserved populations, its ability to overcome barriers to health care for those in greatest need remains unproven. Peer support interventions may help with practical barriers—transportation—or provide encouragement to seek care, while doing little to address systemic discrimination or the financial burdens of illness. Patients' need for privacy, reliance on self and family, or support needs exceeding the capacity of volunteers may make this model inappropriate for many cancer patients. It is probably best seen as part of a spectrum of services.

Although not a limitation of this study, it is important to recognize that peer support alone is unlikely to resolve all cancer health care disparities. Barriers to high-quality palliative and supportive care are complex. A notable finding of this study is that people with serious illness were rarely willing to ask for cancer and palliative care-specific support from Circles of Care volunteers, although many volunteers felt prepared to offer these resources. Given the short-term follow-up of this evaluation, it is not clear whether sharing this type of support will be easier for patients to accept over time or if health care needs change. Historically and presently, persons of minority race or ethnicity experience barriers to access and unfair treatment in health care. Peer support interventions may be capable of bringing much needed information into communities that lack access. African American culture includes a self-preserving sense of privacy and reliance on family, community, and church as

sources of support in times of hardship (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Johnson, Elbert-Avila, & Tulskey, 2005). Innovation in peer support may allow cancer patients and their families to receive community-based practical, emotional, and spiritual support and learn about palliative and supportive care options from trusted sources.

Conclusion

Circles of Care support teams are a promising new model of peer support to provide care, encouragement, and information for African Americans facing serious illness like advanced cancer. Support teams add information on cancer care, palliative care, and emotional and spiritual care to enhance skills of community volunteers. Initial evaluation provides evidence for feasibility, with good reach, adoption, and implementation. Further research should test the efficacy and maintenance of this intervention and its ability to be exported to other settings.

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Figure 1.
Reach—Participation in Circles of Care peer support.

Figure 2.
Community organizations' participation in forming support teams.

Figure 3.
Comparing willingness to offer support to patients' desire for support.

Table 1

Circles of Care Peer Support Training.

Training Content	Training Methods
<ul style="list-style-type: none">• Invocation and call to service• The support team model—building a team, connecting people who want to care with people who need care, and sustaining a team• Offering emotional and spiritual care• Addressing barriers to doctor–patient communication—pain, treatment decisions• Finding community resources—palliative care, supportive care, and hospice• Supporting children and adolescents• Confidentiality and boundaries	<ul style="list-style-type: none">• Short didactic presentations• Reflective exercises• Interactive skill sessions practicing active listening, verbal and nonverbal support• Group discussion and shared problem solving

Table 2

Patient and Support Team Volunteer Characteristics.

	<u>Patients Helped (N = 47)</u>	<u>Support Team Volunteers Trained (N = 193)</u>
	<i>n</i> (%)	<i>n</i> (%)
Age (years)		
Less than 21	1 (2)	5 (3)
21–30	1 (2)	21 (11)
31–40	2 (4)	22 (11)
41–50	9 (19)	28 (15)
51–60	10 (21)	39 (20)
61–70	8 (17)	17 (9)
71 or older	13 (28)	5 (3)
Age not disclosed	3 (6)	56 (29)
Gender		
Female	37 (79)	157 (81)
Male	10 (21)	32 (17)
Gender not disclosed	0	4 (2)
Race/ethnicity		
Asian	0	5 (3)
Black	46 (98)	126 (65)
Hispanic	1 (2)	0
Multiracial	0	1 (1)
Native American	0	3 (1)
White	0	12 (6)
Race/ethnicity not disclosed	0	46 (24)
Friend illness		
Cancer	19 (40)	N/A
Noncancer	27 (57)	N/A
Illness not disclosed	1 (2)	N/A

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