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Circles of Care: Implementation and Evaluation of Support Teams for African-Americans with Cancer

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Abstract

Background—Community-based peer support may help meet practical, emotional and spiritual needs of African Americans with advanced cancer. Support teams are a unique model of peer support for persons facing serious illness, but research is rare. This study sought to 1) implement new volunteer support teams for African Americans with advanced cancer in two distinct regions, and 2) evaluate support teams' ability to improve support, awareness of services, and quality of life for these patients.

Methods—The study used a pre-post design. Community and academic partners collaborated to implement volunteer support teams, and evaluate the intervention using pre-post surveys of volunteers and patients. Patients who declined support teams were also interviewed as a comparison group.

Results—Investigators enrolled and trained 130 volunteers who formed 25 support teams in two geographic regions. Volunteers supported 25 African American patients with advanced cancer (72%) or other diseases. After 2 months, patients with support teams reported fewer needs for practical, emotional and spiritual support on a structured checklist. They more often communicated with someone about their cancer care needs (48% vs. 75%, $p=0.04$), and were more aware of Hospice (4% vs 25%, $p=0.04$), but quality of life scores were unchanged. Comparison patients who refused a support team had fewer support needs at baseline and follow-up, suggesting refusals were based on lack of need.

Conclusion—Coordinated volunteer support teams are a promising new model to provide peer support for African Americans facing cancer and other serious illnesses. Further testing in a pragmatic clinical trial is warranted.

Background

Patients with advanced cancer have complex needs for practical, emotional and spiritual support. Meeting these needs may exceed the scope of professional health services, and effective support depends on patients' family and friends. Observational studies show better emotional and spiritual support is associated with improved quality of life in advanced cancer (Balboni 2007; Balboni 2011; Matthews 2012). Despite these demonstrated benefits, few strategies have been tested to enhance community-based peer support for persons facing advanced stage cancer.

Peer support interventions are used to extend health information and practical, emotional and spiritual support beyond healthcare settings (Fisher 2010). These interventions are based on the socio-ecological theory of community health promotion, which acknowledges the important role of trusted sources for health information within social networks (McLeroy 1988). Peer support providers may be community-based, as in the lay health advisor model, or embedded in health care organizations as patient navigators (Freeman 2006; Brownstein 2004; Lewin 2005; Webel 2010). Community-based peer support may be of particular value to African Americans or other minority populations who face disparities in care (Howlander 2011; Cykert 2010; Cleeland 1997; Anderson 2000; Williams 2008). Peer support interventions have been effective at increasing cancer screening and access to early cancer treatment (Earp 2002; Percac-Lima 2009; Robinson-White 2010). The American Cancer Society's Reach to Recovery program has extended volunteer peer social support and information to thousands of breast cancer patients (Rinehart 1994; Rossiter 2001). Notably, peer support interventions have rarely been studied for persons with advanced illness.

The support team model provides coordinated peer support and may be an optimal way to extend community-based resources for those facing serious or advanced illness. A team rather than an individual extends help, and a designated team leader assesses the needs of the individual with cancer while overseeing support team efforts (Hanson 2012). Support team members learn to 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." The Support Team Network began in 1994, and has been adapted for homebound elders and for persons with dementia and their caregivers (Project Compassion 2010; Support Team Network 2013; Stevens 2009; Buys 2010).

This study builds on our earlier research. After identifying important limitations of the lay advisor model for serious illness, we developed a volunteer peer support team program for African Americans facing advanced cancer, called Circles of Care. We first established the feasibility and acceptability of this approach by training 193 volunteers who created teams to support 47 persons with serious illness (Green 2013; Hanson 2012). In the present study we extend this line of research in two ways – first by exporting the model to a new geographic region, and completing a pre-post process evaluation of effect. Our research aims were to 1) implement new volunteer support teams for African Americans with advanced cancer in two distinct regions, and 2) evaluate support teams' ability to improve support, awareness of services, and quality of life for these patients.

Methods

Academic-community research partnership

To implement support teams in two distinct regions, investigators first expanded the Circles of Care academic-community partnership to participants in a new region of North Carolina. The original region is served by an NCI-designated Comprehensive Cancer Center in a research-intensive academic health system, and by Project Compassion, a non-profit organization with expertise in support team training. Investigators selected a new region with a high density of African American cancer patients and a community-based cancer center willing to partner. Community partners in the new region included two cancer support organizations with strong connections to the local African American community -- the Health Connections Network, a non-profit health navigation organization designed to help cancer patients and the RV Cancer Support Group, a volunteer group organized and led by cancer survivors. Partners had expertise in community-based participatory research, patient advocacy, health ministry, spirituality and health, clinical oncology, and palliative care. Two regionally-based project coordinators were hired within community organizations, and research staff were affiliated with the University and Comprehensive Cancer Center.

Study Design

The peer support intervention was evaluated using a pre-post study design, in which patients with a support team served as their own historical controls. Patients who were approached but declined Circles of Care support teams were invited to serve as a comparison group to understand the experience of similarly ill patients who refuse this form of supportive care. All data were collected by coordinators and research staff in baseline and follow-up structured interviews with both support team volunteers and with patients done 2 months after their enrollment. All enrollment and data collection was completed between January 2011 and March 2012.

Participants and Recruitment

Study participants comprised two groups – support team volunteers and persons with advanced cancer. Community project coordinators and research staff worked together to recruit study participants. Volunteers were eligible if they completed support team training and agreed to participate in Circles of Care; some volunteers had personal or family experience with cancer, but this was not required. Support team volunteers were non-professionals recruited from the same geographic and social communities of participating cancer patients. Recruitment was done through community contacts with African American church leaders and health ministries and patients' own social networks. Publicity materials were included in church bulletins, in cancer center clinics, and in news media reaching African-American communities, with in-person contacts at 22 churches, 13 health care or cancer advocacy organizations, and 7 other community-based organizations such as senior centers.

Patients were eligible if they identified themselves as African American and self-reported advanced cancer or comparable serious illness. Advanced cancer stage was described in recruitment materials but patients were not required to know diagnosis or stage to

participate, and investigators did not review health records. Persons with cancer were recruited using two approaches – community contacts and cancer center clinic recruitment. Community contacts included African American church leaders and the social networks of trained Circles of Care volunteers. In clinics, African American patients were given written and in-person information about the support team intervention study during wait times or visits, with follow-up by telephone.

All support team members and patients gave written informed consent for their participation. Study procedures were approved by the Protocol Review Committee of the Lineberger Comprehensive Cancer Center and the Institutional Review Boards (IRB) for the University of North Carolina Schools of Nursing and Public Health and for the Zimmer Cancer Center.

Intervention

Members of the community-academic partnership offered all volunteers free training on practical, emotional and spiritual support for cancer. The training was offered several times in both geographic regions. Training content was previously described in the developmental phase of this research, and includes the support team model, approaches for practical, emotional and spiritual support, support for children, and confidentiality and boundaries concerns (Hanson 2012). It is highly structured, with didactic and interactive components. Team leader training required 6 hours, while team members could opt for 3 hour training. Volunteers also received advance care planning tools and region-specific information on pain management or palliative care providers, hospice agencies, and other community cancer support services.

Once volunteers were trained, project coordinators matched each patient with a support team consisting of 3 –10 volunteers. The size of the team was based on the patient’s perceived need for support, and volunteers were matched based on proximity and any common social network connections. Volunteers were trained to do “what they like to do, when they can do it, in a coordinated way.” Support activities were offered by the volunteers based on their time and willingness to provide specific types of support, and the needs expressed on the patient checklist. (Table 3) Support teams met regularly, and worked together to extend community-based practical, emotional and spiritual support, and share cancer resource information. Community project coordinators checked in regularly with support team volunteers throughout the study period to address any challenges or questions.

Data collection: patients

Study measures were collected from patients using baseline and 2-month follow-up written surveys. All patients, including those who accepted a support team and the comparison patients who refused a support team, completed a baseline survey. Survey items included age, gender, and cancer diagnosis and stage (if known) and questions on support needs, awareness of services to help with pain and symptoms, and health-related quality of life. Surveys were self-administered with stand-by assistance from the project coordinator. To measure support needs patients responded to a checklist of items to indicate whether they felt they needed but did not have specific types of support, including practical, emotional, spiritual, quality of life, advocacy and cancer-specific support. This checklist was based on

an existing instrument used by Project Compassion for support team assessments, and the list of items is represented in Table 3. Awareness of services to help with pain and symptoms was measured using a single open-ended question, developed for this study, “Do you know about specialists – doctors, nurses or other health providers – who could help with treatment of pain and other symptoms if your own health team isn’t helping enough?” Responses were coded for content on awareness of pain specialists, palliative care or supportive care specialists, or hospice. Patients reported health-related quality of life using the FACIT-Sp, a modification of the 27-item FACT-G with 12 additional items about spiritual well-being; instruments with established psychometrics for internal consistency, test re-test reliability and validity (Cella 1993) (Peterman 2002). These 39 items are rated 0-4 and summed, for a total score range of 0-156, and higher scores indicate better quality of life. At 2 months’ follow-up, patients used the same items to report support needs, awareness of services, and health-related quality of life. Follow-up surveys for patients were self-administered or, if preferred, completed as interviews by research staff.

Data collection: volunteers

To evaluate training, volunteers also completed a baseline self-administered survey providing demographic data and yes / no responses to whether they felt prepared to provide a checklist of support activities, grouped as practical, emotional, spiritual, quality of life, advocacy, or cancer-specific support. This checklist paralleled the patient checklist. Two months later volunteers used this same list to report on the actual support they offered to patients in Circles of Care. Volunteers’ follow-up surveys were completed electronically using a Qualtrics survey. A small number of these surveys were administered in-person by the research staff for volunteers without computer access.

Analysis

Analysis to meet the first aim was a simple count of the numbers of volunteers trained, teams formed and patients served. Analysis to meet the second aim, to evaluate the effect of support teams used pre-post comparison of the percent of patients endorsing each type of support need on the checklist, percent of patients who named a resource – hospice, palliative care, pain specialist -- to help with pain and symptoms, and average FACIT-Sp scores.

To provide a descriptive evaluation of training for Circles of Care volunteers, investigators compared data from volunteers’ baseline reports of preparation to provide support to actual support they reported offering after 2 months’ follow-up. All data were analyzed as simple frequencies with bivariate comparisons using chi-square testing for frequencies and t tests for FACIT-Sp scores. To examine potential sustainability, investigators reported the percent of trained volunteers who remained active at 2 months, and continuation of intervention activities after the end of grant funding.

Results

Implementation of new volunteer support teams in two regions

The Circles of Care study enrolled 130 volunteers, 30 of whom also completed additional training to become team leaders (Table 1). A total of 25 Circles of Care support teams were

successfully created in two distinct geographic regions covering four counties. Support team volunteers were usually women, and 87% were African American. The study enrolled 48 patients, including 25 who accepted the support team intervention and 23 who did not want a support team and served as a comparison group. (Table 2) Most patients in the intervention group were women aged 51 or older, and all were African American. Most patients with support teams had cancer (72%) while the remainder had serious non-cancer diagnoses including chronic lung disease, dementia, and Parkinson's disease.

Patients in the comparison group were nearly all women with cancer, and were similar in age and stage of disease to patients who desired support teams. These patients, who had decided against having a support team, also reported somewhat better baseline health-related quality of life (117 vs 103, $p<0.05$).

Effect of the intervention on support needs

Using pre-post comparison, patients who had Circles of Care support teams reported fewer support needs on the checklist after 2 months. (Table 3) Using practical needs as an example, 60% of patients reported unmet needs for help with errands or household tasks at enrollment, while only 20% and 15% reported these areas of unmet need after 2 months in the program. Emotional and spiritual support needs declined more than other categories on this checklist; however, there were downward trends in all categories of unmet need queried. Despite having a serious illness, patients with a Circles of Care support team reported fewer needs at follow-up, with statistically significant reductions in specific practical, emotional and spiritual support needs. They also reported fewer needs for help finding community resources and services (60% vs 15%, $p<0.05$). Comparison patients who refused a support team had very few support needs at baseline and follow-up, suggesting their refusals were based on lack of need rather than rejection of the type of support offered.

Effect of the intervention awareness of services and quality of life

After experience with a support team, more patients identified Hospice as a source of help for pain or symptoms (4% vs. 25%, $p=0.04$). Awareness of palliative care, pain specialists or other supportive care professionals did not change, and patients reported no significant change in health-related quality of life (103 vs. 106, $p=NS$).

Compared to baseline, patients with a support team for 2 months became more likely to have communicated with someone about their cancer care needs (48% vs. 75%, $p=0.04$), usually health care providers or family members. One patient described her experience during the interview, "My husband and I have been pretty open with everyone about my needs – Circles of Care, church members, family and friends. I want others to know my need so they can better understand my needs. Circles of Care members are now more like family members. The more people you know the better your support!"

Effectiveness of volunteer training

After baseline training, the percent of support team volunteers who felt prepared and able to provide different types of support matched or exceeded the percent of patients who requested each type of support. (Figure) Patients most often reported needs for emotional,

spiritual and advocacy support, including friendly visits and calls, prayer, spiritual conversation, and help finding community resources. Volunteers indicated the strongest preparation for these areas of service, although over 40% felt prepared to offer support in every category.

By 2 months after training, volunteers also reported they had actually delivered on the promise of support activities to a subset of patients who expressed a need. The most common type of support was emotional, provided by 24% of trained volunteers. The least common type of support within this time frame was provision of information on cancer and palliative care resources, provided by 3% of volunteers.

Potential sustainability of the intervention

The support team model builds on existing social networks and often provides training to persons who already serve as caregivers and natural helpers in their communities. After 2 months of the support team intervention, 104 (80%) volunteers remained active in support teams, and 44 (34%) reported a direct role giving supportive care during this time frame. In both geographic regions, local non-profit organizations have continued developing and training support teams more than one year after the end of grant funding.

Discussion

Patients with advanced cancer have extensive needs for practical, emotional and spiritual support which often exceed the capacity of medical and professional services. This study provides the first evidence for volunteer support teams as a promising new approach to help meet practical, emotional and spiritual needs during serious illness. A community-academic partnership provided training and team coordination for volunteers who supported 25 seriously ill patients. After two months, patients reported greater support for practical, emotional and spiritual needs, and were more often aware of Hospice services. Patients who refused support teams had fewer needs, suggesting the model is reaching the appropriate patients. Although expertise about the support team model began within a regional non-profit organization, this study showed that training and implementation of teams could be exported to a new region served by a different cancer center. Support team activities have been continued by non-profit organizations in both regions more than one year after the end of grant funding, indicating potential for sustainability.

The support team model builds on a compelling body of evidence for peer support interventions in preventive and early cancer care. This study is the first formal evaluation of peer support using a team approach, and thus better matched to the greater practical, emotional and spiritual supportive care needs of people with advanced illness. Support team volunteers receive training and are encouraged to work together in a purposeful way, ensuring that team support is coordinated and better matched to a patient's needs. Several preliminary reports of support teams have been published. Stevens trained 7 support teams for caregivers of patients with Alzheimer's dementia (Stevens 2009). Investigators from the University of Alabama, where the Support Team Network originated, have reported on application of support teams to the delivery of meals to homebound elders (Buys 2010). A

similar model has been applied in mental health services to promote sustained employment (Spagnolo 2011). None of these studies have included structured evaluation of the model.

Although this study represents the next critical step in the evidence base for a new form of peer support, some caution in interpretation is warranted. First, the pre-post study design and short follow-up period are appropriate for early testing but limit internal validity. The evaluation time frame of 2 months did not permit measurement of important health behavior outcomes such as access to formal supportive care services or hospice. Overall health-related quality of life did not change, likely due to the very short follow-up timeframe. Support teams typically work with patients for many months, and outcomes after 6-9 months may be more appropriate to capture true effects. This study provides data on a comparison group of patients who did not want a support team, but future research should use randomized or historical controls to strengthen validity. Second, support teams are a complex intervention requiring meaningful academic-community partnership. Many novel interventions are dependent on the charismatic leadership of a particular group or the unique advantages found in the original community. One design strength of this study is replication of the support team intervention in two distinct geographic regions. However, additional evidence for exportability is needed to show that support teams are a generalizable intervention. Third, while the support team intervention was targeted for African American advanced cancer patients, support teams sometimes reached out to persons who did not know cancer stage or who had other forms of serious illness. Review of North Carolina Cancer Registry data shows that, on average, 104 African Americans are diagnosed each year with Stage III or IV breast, colon or lung cancer in the affected counties (North Carolina Central Cancer Registry 2005-2009). During a 1 year period this intervention reached approximately one quarter of this population. The narrow focus of the intervention by race and cancer stage may be difficult to maintain; future studies should test the intervention in a more diverse population.

Conclusion

Coordinated volunteer support teams are a promising new model to provide peer support, with potential to enhance community-based supportive care for patients living with cancer. Patients who accept support teams have unmet needs for practical, emotional and spiritual care, and support teams effectively address these needs. A pragmatic clinical trial is warranted, to examine longer term outcomes for a larger and more generalizable group of patients.

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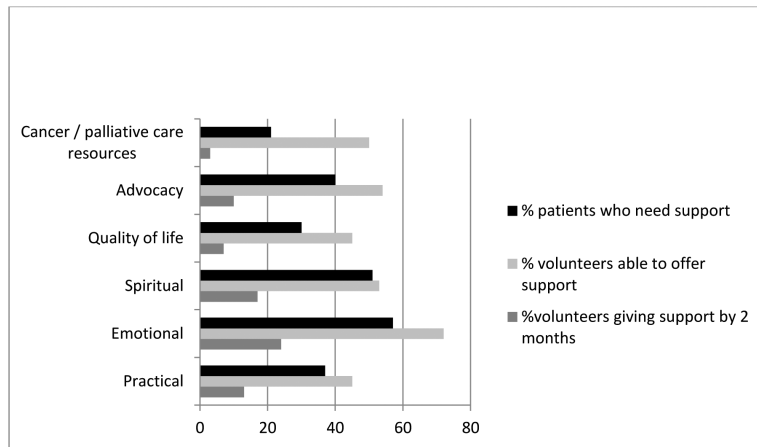


Figure.
Patients in Need and Volunteers Able to Offer Support

Table 1

Support Team Volunteers

Characteristics	N=130 n (%)
Age*	
21-30	16 (12)
31-40	11 (8)
41-50	34 (26)
51-60	28 (22)
61-70	33 (25)
71 or older	4 (3)
Gender	
Female	107 (82)
Male	23 (18)
Race/Ethnicity*	
Caucasian	8 (6)
African American	113 (87)
Other	5 (4)
Training Completed	
Support Team Orientation	100 (77)
Leadership Training	23 (18)
Both	7 (5)

* 4 participants did not report age, race

Table 2

Patient Characteristics

	Intervention group N=25 N (%)	Comparison group N=23 N (%)
Age		
<41	3 (13)	0 (0)
41-50	3 (13)	4 (17)
51-60	9 (38)	10 (44)
61	9 (38)	9 (39)
Gender*		
Female	18 (72)	22 (96)
Male	7 (28)	1 (4)
Quality of life* (FACIT-Sp, range 0-152)	103	117
Cancer Diagnosis*	18 (72)	22 (96)
Stage 1-2 cancer	2	2
Stage 3-4 cancer	11	11
Unknown stage cancer	5	9

Note. Percents may not sum to 100% due to rounding. One patient did not report age.

*
p<0.05

Table 3

Effect of Intervention on Unmet Support Needs after Two Months

	SUPPORT NEEDS: PATIENTS WITH SUPPORT TEAM		SUPPORT NEEDS: PATIENTS WHO REFUSED SUPPORT TEAM	
	Baseline N=25	2-mo FU N=20	Baseline N=23	2-mo FU N=17
<i>PRACTICAL SUPPORT</i>				
Help with transportation	9(36)	6(30)	4(17)	2(12)
Respite	9(36)	5(25)	1(4)	1(6)
Meals	11(44)	5(25)	1(4)	2(12)
Errands or shopping	15(60)	4(20)*	1(4)	1(6)
Household tasks	15(60)	3(15)*	3(13)	2(12)
Yard work	7(28)	1(5)	4(17)	3(18)
Basic needs	6(24)	3(15)	1(4)	0
Personal hygiene or beauty care	2(8)	4(20)	2(9)	2(12)
<i>EMOTIONAL SUPPORT</i>	Baseline N=25	2-mo FU N=20	Baseline N=23	2-mo FU N=17
Friendly visits	19(76)	4(20)*	5(22)	5(29)
Calls or check-ins	19(76)	4(20)*	8(35)	4(24)
E-mails	8(32)	1(5)*	4(17)	3(18)
Cards or notes	13(52)	5(25)*	9(39)	3(18)
Shared time together	15(60)	4(20)*	5(22)	4(24)
Visits or calls with family members	11(44)	4(20)	1(4)	3(18)
<i>SPIRITUAL SUPPORT</i>	Baseline N=25	2-mo FU N=20	Control N=23	Control N=17
Prayer	19(76)	4(20)*	11(48)	0
Communion	11(44)	4(20)	2(9)	2(12)
Spiritual conversation	16(64)	2(10)*	6(26)	1(6)
Fellowship	15(60)	5(25)*	5(22)	1(6)
Help getting to worship or meetings	7(28)	2(10)	4(17)	1(6)
Spiritual support for family members	9(36)	2(10)	1(4)	2(12)
<i>QUALITY OF LIFE SUPPORT</i>	Baseline N=25	2-mo FU N=20	Baseline N=23	2-mo FU N=17
Social outings	16(64)	6(30)*	8(35)	3(18)
Gardening	5(20)	2(10)	2(9)	1(6)
Help with hobbies	8(32)	3(15)	3(13)	1(6)
Help with computer access	7(28)	4(20)	4(17)	2(12)
Help with pet care	2(8)	1(5)	2(9)	0
<i>ADVOCACY AND RESOURCE SUPPORT</i>	Baseline N=25	2-mo FU N=20	Baseline N=23	2-mo FU N=17
Finding community resources and	15(60)	3(15)*	11(48)	4(24)

	SUPPORT NEEDS: PATIENTS WITH SUPPORT TEAM		SUPPORT NEEDS: PATIENTS WHO REFUSED SUPPORT TEAM	
services				
Help with problem solving in health care needs	10(40)	4(20)	8(35)	5(29)
Help organizing paperwork, records or bills	5(20)	2(10)	2(9)	2(12)
CANCER SPECIFIC SUPPORT	Baseline N=25	2-mo FU N=20	Baseline N=23	2-mo FU N=17
Accompanying to doctor visits	4(16)	1(5)	1(4)	0
Help communicating with doctor or providers	1(4)	1(5)	2(9)	0
Finding information about cancer treatment options	7(28)	1(5)	7(30)	2(12)
Finding information about life-sustaining treatment options	7(28)	3(15)	5(22)	4(24)
Finding cancer support groups	5(20)	2(10)	4(17)	5(29)
Finding help for pain or other symptom control	4(16)	1(5)	4(17)	1(6)
Finding information on hospice services	1(4)	1(5)	1(4)	1(6)
Finding information on Power of Attorney / living wills	6(28)	3(15)	6(26)	4(24)
Support and information for family members	6(28)	2(10)	5(22)	3(18)

* p<0.05 pre-post comparison