

Can Community Health Workers Increase Palliative Care Use for African American Patients? A Pilot Study

Ramy Sedhom, MD¹; Richard Nudotor, MD, MPH²; Karen M. Freund, MD, MPH³; Thomas J. Smith, MD⁴; Lisa A. Cooper, MD, MPH^{5,6}; Jill T. Owczarzak, PhD⁶; and Fabian M. Johnston, MD, MHS²

QUESTION ASKED: Are community health workers (CHWs) a feasible intervention to increase palliative care (PC) uptake for African Americans with advanced cancer?

SUMMARY ANSWER: Use of a CHW to address PC domains and advance care planning (ACP) for African American patients with advanced cancer is feasible.

WHAT WE DID: This feasibility study describes training and recruitment of a CHW, and patient identification, enrollment, and retention. The CHW intervention consisted of a comprehensive assessment of multiple PC domains and the social determinants of health. Ongoing support was tailored on the basis of iterative assessment of patient needs. We measured how often patients met with the CHW and the impact on ACP and PC utilization.

WHAT WE FOUND: African American patients with advanced cancer were willing to include a CHW as a part of their clinical care team. Using shared experiences, CHWs were able to elicit patient values and increase referral to PC and ACP documentation. Psychological distress and depressive symptoms also improved.

BIAS, CONFOUNDING FACTORS, DRAWBACKS: This study was a feasibility trial and limited to a single center. Difficulties with enrollment were identified as a key barrier.

REAL-LIFE IMPLICATIONS: CHWs offer an opportunity to address gaps in PC for African Americans with cancer. Continuous work is needed to standardize the approach to hiring, training, and workflow for CHWs and to demonstrate their impact on important patient outcomes.

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ASSOCIATED CONTENT

Appendix

Data Supplement

Author affiliations and disclosures are available with the complete article at ascopubs.org/journal/op.

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abstract

PURPOSE African American patients with cancer underutilize advance care planning (ACP) and palliative care (PC). This feasibility study investigated whether community health workers (CHWs) could improve ACP and PC utilization for African American patients with advanced cancer.

METHODS African American patients diagnosed with an advanced solid organ cancer (stage IV or stage III disease with a palliative performance score < 60%) were enrolled. Patients completed baseline surveys that assessed symptom burden and distress at baseline and 3 months post-CHW intervention. The CHW intervention consisted of a comprehensive assessment of multiple PC domains and social determinants of health. CHWs provided tailored support and education on the basis of iterative assessment of patient needs. Intervention feasibility was determined by patient and caregiver retention rate above 50% at 3 months.

RESULTS Over a 12-month period, 24 patients were screened, of which 21 were deemed eligible. Twelve patients participated in the study. Patient retention was high at 3 months (75%) and 6 months (66%). Following the CHW intervention, symptom assessment as measured by Edmonton Symptom Assessment System improved from 33.8 at baseline to 18.8 ($P = .03$). Psychological distress improved from 5.5 to 4.7 ($P = .36$), and depressive symptoms from 42.2 to 33.6 ($P = .09$), although this was not significant. ACP documentation improved from 25% at baseline to 75% at study completion. Sixty-seven percentage of patients were referred to PC, with 100% of three decedents using hospice.

CONCLUSION Utilization of CHWs to address PC domains and social determinants of health is feasible. Although study enrollment was identified as a potential barrier, most recruited patients were retained on study.

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INTRODUCTION

Although treatment for cancer has improved and death has decreased,¹ disparities in outcome remain for minority patients.² The delivery of high-quality end-of-life (EOL) care remains challenging for African American patients with cancer.³ Compared with Caucasians, African American patients are less likely to share care preferences or complete advance directives, have a living will, or have a do-not-resuscitate order.⁴⁻⁶ They are more likely to choose aggressive care for incurable illness and less frequently access hospice services.⁷ Institutional, individual, and cultural barriers partially explain these disparities in EOL care quality.⁸⁻¹⁰ Although palliative care (PC) is endorsed by multiple medical societies^{11,12} and has potential to bridge disparities in EOL outcomes,^{13,14} uptake is limited in oncology practice.¹⁵

Multiple rigorously studied interventions have reduced disparities in cancer care.¹⁶⁻¹⁹ Community health workers (CHWs) represent one strategy to improve care quality within fragmented health systems.^{20,21} CHWs are trusted individuals from local communities,²² who undergo training to support advocacy, community building and outreach, cultural competency, care coordination, and system navigation to promote health behavior change. Several studies demonstrate effectiveness in chronic disease control,²³ mental health,²⁴ care quality,²⁵ and health utilization.²⁶ CHWs have worked with at-risk populations,^{27,28} with some interventions targeting PC domains.^{17,19,29} Yet, the challenges of conducting PC trials are well-documented, with difficulties in participant recruitment, high rates of patient attrition, and missing data because of progressive disease and death.³⁰

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Despite the evidence that advance care planning (ACP) improves EOL outcomes,³¹⁻³³ clinicians have limited time²⁹ and are often averse to difficult conversations.³⁴ Although PC teams assist in these discussions, there remains a workforce shortage and providers are difficult to access outside the hospital setting.³⁵ Therefore, novel strategies are needed to ensure appropriate communication with seriously ill patients and families, particularly for communities historically disenfranchised by health systems.^{36,37} In this feasibility study, we sought to establish the use of a CHW intervention to increase utilization of PC by African American patients with advanced cancer by removing barriers to assessment and management of PC domains.³⁸ Herein, we focus on infrastructure development, training of a CHW, study retention, and barriers to implementation.

METHODS

The aim of this pilot study was to investigate the feasibility of a CHW intervention to improve PC utilization by African American patients with advanced cancer. All aspects of the intervention content were determined and reviewed through engagements with stakeholders along the PC continuum via our previous work.³⁹ Implementation science frameworks (Consolidated Framework for Implementation Research and Reach, Effectiveness, Adoption, Implementation, and Maintenance) were used from study inception to identify crucial components of the intervention to ensure sustainability.⁴⁰ Five stakeholder focus groups, composed of 13-15 participants, informed and refined the intervention prior to piloting. As per the seven P's taxonomy, stakeholder engagement included providers (oncologists, CHWs, and PC clinicians), patients and their caregivers, purchasers or hospital administrators, policy makers, and principal investigators (quality, implementation, and PC researchers).⁴¹ The remaining two Ps of the taxonomy (payers and product makers) were not included given the scope of the question.

Participants were engaged across longitudinal stakeholder engagement sessions. A semistructured guide was prepared by the study team. The guide focused on identifying the behaviors that most consistently affect PC use and the viability of CHWs as a mechanism to address these behaviors. This included barriers and facilitators informed by Consolidated Framework for Implementation Research and Reach, Effectiveness, Adoption, Implementation, and Maintenance and culminated with stakeholder input regarding the developed implementation interventions. The intervention was deemed feasible if the study retention rate was > 50% at 3 months. Study retention was chosen as the metric given known attrition rates of 50% and higher within PC trials and the multilevel barriers to PC utilization for African American patients.⁴²⁻⁴⁴ Clinicians and the CHW met monthly to share program success and challenges and used peer-to-peer communication to maximize program uptake.

CHW Selection, Navigator Framework, and Training

Invitations were sent to recruit a CHW from the local community. We required a bachelor's degree or at least three years of experience as a CHW, but maintained that the CHW was not a licensed provider, such as a nurse or social worker. The recommended characteristics included being empathetic, communicative, and comfortable with discussions on spirituality, and given our intervention, of African American race. Following selection, the CHW received 2 weeks of skills training and focused on patient and caregiver empowerment, value assessments, and symptom management. Our goal for the navigator was to serve as a link for patients and caregivers to oncologists and PC providers. In this role, CHWs would provide psychosocial support and general care information and facilitate ACP, symptom management, and PC uptake. These objectives provided the foundation of navigator training with a focus on helping patients achieve optimal health, rather than emphasizing treatment.

The navigator training curriculum was developed and delivered by a multidisciplinary team that included expert faculty (from oncology, PC, nursing, social work, and chaplain services), with independent NIH funding in health disparities, PC, and patient communication, and experience working with PC teams and/or African American religious institutions. We used multiple training modalities, for 9 hours per day. These included self-paced modules, in-person workshops, and rotations on the PC service and outpatient hospice. The CHW received feedback on communication skills, from both experienced nurse practitioners and the director of palliative medicine (T.J.S.). Core training components included the following:

- Navigation basics: focused on health promotion, empowerment, and navigation principles. This included communication skills, distress screening, and problem solving to overcome barriers to PC utilization, experiences of the patient with cancer, and compassion fatigue.
- Advanced navigation: Topics included reasons for emergency room visits, cultural, physical, psychological, and spiritual aspects of care, caregiver interactions, motivational interviewing, and social determinants of health.
- Advance care planning: CHWs were trained to facilitate ACP conversations with patients and caregivers. Content included choosing a healthcare proxy, documenting care preferences, and implications uploading documents into the electronic health record (Fig 1).

Target Population and Triage Mechanisms

Patients were recruited during scheduled clinic visits at an National Cancer Institute-designated comprehensive cancer center. Inclusion criteria included (1) self-identifying as African American, (2) diagnosed with an advanced solid

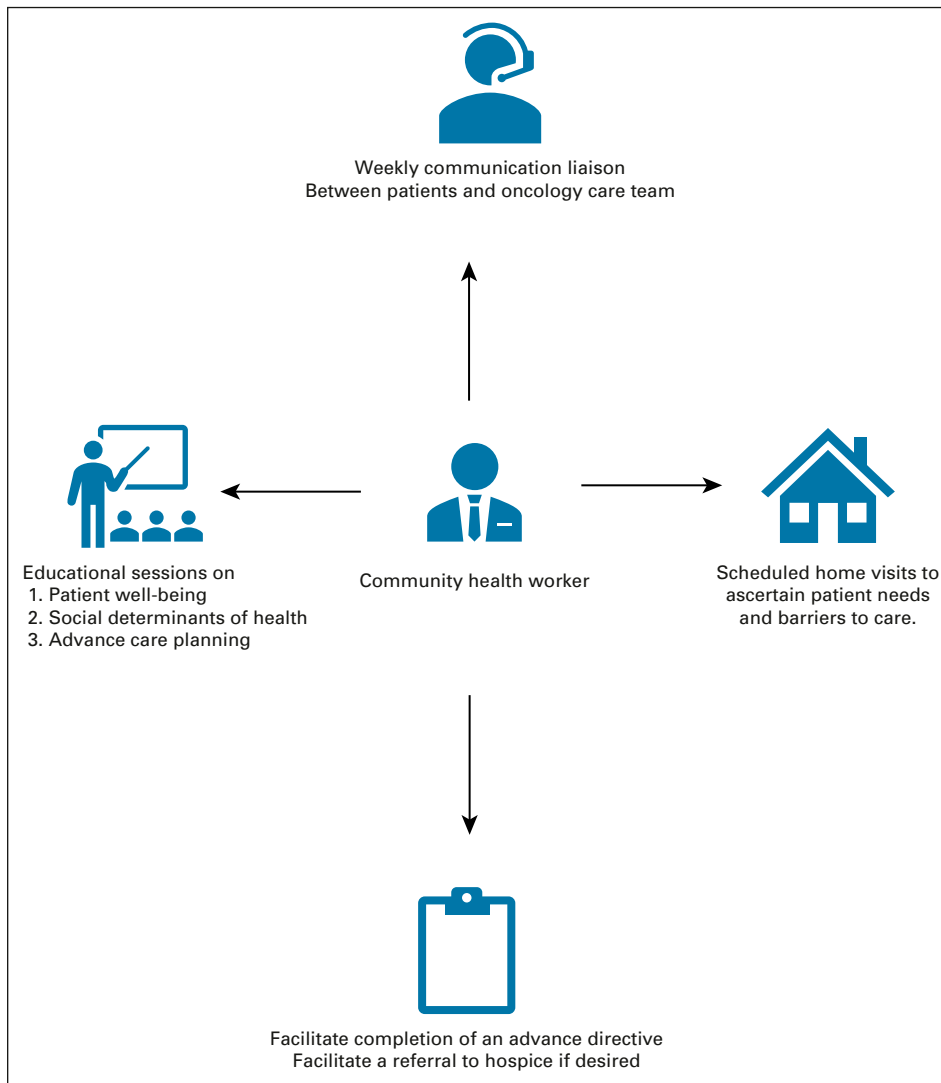


FIG 1. The components of the community health worker interventions.

organ cancer (stage IV or stage III disease with the palliative performance score < 60%), and (3) age 18 or older. Patients were assessed for enrollment regardless of timing of diagnosis or disease progression, given high levels of distress, psychosocial needs, and symptoms appropriate for supportive care.^{45,46} These criteria also align with recommendations by ASCO.¹¹ Our exclusion criteria included pregnant women and patients with substance use disorder.

Patient Navigation

Following screening, eligible patients were enrolled and encouraged to select a caregiver who would be consented for the study, working together as dyad. However, patients without a designated caregiver were also enrolled. Following enrollment, research assistants met with patients to complete these surveys at baseline and 3 months: National Cancer Comprehensive Network Physical and Psychological Distress (Distress Thermometer), Center for Epidemiological Studies-Depression (CES-D), Edmonton Symptom

Assessment System Revised Version (ESAS-r), and Functional Assessment of Chronic Illness Therapy—Palliative Care (FACIT-Pal).⁴⁷⁻⁵⁰

The Psychological Distress Scale is a single item asking patients to rate their distress on a scale of 0 = none to 10 = extreme distress.⁴⁷ A mark of five or above indicates a need for intervention. The CES-D assesses the number, types, and duration of depressive symptoms through 20 items, on a 4-point Likert scale ranging from 0 to 3. Scores range from 0 to 60 with higher scores indicating more depressive symptoms. ESAS-r consists of ten 0-10 self-report scales that evaluate a combination of psychological and physical symptoms, in addition to a global sense of well-being, with higher scores indicating more severe symptoms. The FACIT-Pal is a 46-item measure of self-reported health-related quality of life. Scores range from 0 to 184, with higher scores indicating better quality of life.

One week following enrollment, the CHW coordinated an initial visit with the patient at their home or a clinical location. A semistructured interview guide was followed in the first two sessions, on the basis of previous stakeholder engagement, to learn patient stories and understand individual needs.³⁸ These conversations allowed for tailored, patient-driven action plans. Patient educational sessions had content organized in three domains: patient well-being, social determinants of health, and ACP. Participants were contacted by phone weekly. Caregivers were strongly encouraged to participate in the educational sessions, but this was not required. Each patient was offered five CHW visits over the study period with each visit recorded and transcribed for qualitative assessment. CHWs communicated with the oncology team to discuss any perceived patient issues, which may necessitate PC referral. Similarly, the oncology and PC teams communicated with the CHW any patient-related concerns. The CHW office was co-located with the PC team to allow regular communication and emotional support.

Navigation Tools and Outcome Measures

The CHW used distress screening to identify unmet biopsychosocial needs to streamline navigation services.⁵¹ Outcome measures included (1) attitudes and preferences toward CHW discussions for PC assessed by transcribed recordings, (2) number of advance directives completed and present in the medical record, (3) number of patients aware of hospice and referred, (4) distress thermometer, (5) FACIT-Pal, (6) ESAS-r, and (7) CES-D. Process measures included the number of sessions missed, reasons for nonadherence, duration of each session, referrals to PC, and healthcare utilization (number of hospitalizations and visits to the emergency department).

Data were entered into a database and audited for accuracy. Descriptive statistics were computed, and distributions were examined for normality. Nonparametric analysis was used, as is appropriate for sample sizes of 20 or fewer subjects. The study used the Giorgi method for qualitative data analysis,⁵² to develop descriptions related to human experiences—in this case, patient navigation with a CHW. The first author (R.S.) drafted the initial coding scheme and revised it following the initial two transcripts, incorporating research team feedback. Each meaning unit was identified and coded using NVivo⁵²; units were organized into groups as themes emerged, and the analysis was refined in this iterative process. Two independent coders (R.S. and R.N.) analyzed 20% of all transcripts independently, and differences were reconciled by consensus. Kappa coefficients were generated to evaluate coding precision, and the final kappa (> 0.85) indicated a high level of agreement. The Johns Hopkins Medical Institutional Review Board approved this study.

RESULTS

From August 1, 2018, to August 1, 2019, patients were screened, approached, and enrolled. Twenty-four consecutive patients were assessed for eligibility with nine patients ineligible for either stage of disease or performance status. Thus, 15 patients were eligible and consented. Three patients were lost to follow-up after signing consent, leaving 12 patients to undergo the full intervention. Participants had a mean age of 58 years (range, 37-72), and most patients were female (67%). The majority were unemployed (53%); only 25% graduated from college, and 33% were married. Cancer diagnosis included GI (50%), sarcoma (33%), and lung (8%) and breast cancers (8%). Most patients (85%) had at least 1 comorbidity (Table 1). The majority of patients (75%) were on active therapy.

On average, the CHW spent 40 minutes per session with each patient and was able to complete at least four sessions with 67% of participants. The majority of patients were never hospitalized (75%), and multiple (> 1) visits to the emergency room were infrequent (25%). At baseline, only 25% of patients had completed an advance directive. This increased to 75% by the end of the study. All advance directives were documented in the chart, with the exception of 1 participant. The majority of patients (67%) were referred to PC. The patient retention rate was high at 3 months (9 of 12 or 75%). Three patient deaths were noted before the 6-month follow-up, and all died with hospice. One additional patient was lost to follow-up at 5 months, and therefore, retention remained high at 6 months (8 of 12 or 66%).

Recorded transcripts detailed patient and caregiver reception toward CHW discussions regarding PC. Patients and caregivers reported a sense of comfort discussing EOL care informally outside of the physician's office. Several patients felt it was important to receive guidance from their pastor, and two expressed frustration sharing bad news with family members. In three cases where ACP was deflected, the CHW reminded families of available resources, such as social work, nursing, and chaplains. Below are some examples:

- In one instance, the CHW focused on the importance of ACP and how it can prevent an unwanted outcome, such as dying in the hospital alone and without family. This was in response to a patient comment that his aunt should have never died alone.
- For at least two patients, the CHW discussed legacy building and identified religion as important when considering EOL choices. The CHW facilitated conversation with their pastor for support and followed up in future meetings.

Patient-reported outcomes are outlined in Appendix Table A1, online only. At baseline, patient distress, as measured by the National Comprehensive Cancer Network distress

TABLE 1. Sociodemographic and Clinical Characteristics of Enrolled Participants

Characteristic	N = 12	% dwd
Sex		
Male	4	33
Female	8	67
Age		
Mean (range)	57.7 (37-72)	
Race and ethnicity		
African American	12	100
Education		
High school	3	25
Some college	1	8
Associate degree	2	17
Graduate	3	25
Unknown	3	25
Employment status		
Unemployed	6	50
Employed	3	25
Retired	3	25
Marital status		
Never married	5	42
Married	4	33
Divorced	1	8
Widowed	2	17
Type of cancer		
GI	6	50
Breast	1	8
Lung	1	8
Sarcoma	4	33
Comorbidities ^a (N = 12)		
None	2	17
Cardiovascular	10	83
Respiratory	5	42
Diabetes	6	50
Renal	4	33
GI	2	17

Abbreviations: CHW, community health worker.

^a(Comorbidities): Some patients had multiple comorbidities and provided multiple answers.

Thermometer, was 5.5 (5 is threshold for intervention). At 3-month follow-up, mean distress numerically improved to 4.7 ($P = .36$), as did depressive symptoms, 42.2 at baseline to 33.6 at follow-up ($P = .09$), although not significantly. Symptoms, as measured by the ESAS-r, significantly improved from 33.8 at baseline to 18.8 at follow-up ($P = .03$). Physical function remained stable as measured by FACIT-Pal ($P = .4$) (Data Supplement, online only).

Feasibility challenges are presented in Table 2. Only 15 patients were accrued over 12 months, which was largely driven by research staff turnover. Although 67% of patients were ultimately seen by PC, visits were not concurrent with oncology appointments. The CHW reported initial discomfort navigating PC domains, which improved over time: "It felt different because I understood more than before and became more at ease." Communication challenges between patients and the CHW were embedded in prior family experiences, reflecting fear of loss, dying alone, and a painful death. Still, patients felt that communication with the CHW was meaningful: "You've been a tremendous help in peaceful talking and getting around. Like, the challenge is not there as much as I think it would have been had you not been put in place."

DISCUSSION

To our knowledge, this is the first study to evaluate the feasibility of a CHW to improve PC utilization and promote ACP for African American patients with cancer. We found this intervention feasible with a high retention rate (75% at 3 months and 66% at 6 months). Additionally, there was a potential benefit for some patients, as evidenced by the PC referral rate, number of completed advance directives, and universal utilization of hospice by decedents. Importantly, this study addresses two major gaps that allow failure of PC to propagate, namely, (1) evaluation of implementation and dissemination in study planning and (2) addressing the needs of underrepresented minorities.

Although we were successful in accruing and retaining patients, several feasibility challenges were noted (Table 2). Patients and caregivers were reluctant to schedule five visits with the CHW and expressed frustration arranging additional visits with PC teams. Closer collaboration is needed to minimize the burden of additional visits. Educational session content can be combined into fewer sessions to meet patient preferences. Patient outreach was challenging; in one case, the CHW called eight times before scheduling the initial patient visit. Oncologists were less experienced using palliative performance scale, as opposed to Eastern Cooperative Oncology Group, which created challenges in recruitment. Despite these limitations, flexibility with the mode of patient education session delivery, as deemed appropriate by the patient and caregiver dyads and the CHW, limited inconveniences.

Although health systems employ various personnel on healthcare teams, few share common background with minority patients. In our pilot study, only 25% of patients had graduated college and 50% were unemployed. Social network theory⁵³ supports the notion that CHWs contribute meaningfully to healthcare teams by establishing trust, support, and practical guidance through shared experiences.⁵⁴ In this study, the CHW engaged with patients traditionally marginalized from the healthcare system.^{36,37} More than 60% of patients met with the CHW more than

TABLE 2. Feasibility Challenges Encountered in Pilot Study

Challenge	Potential Solutions	Conceptual Benefits
Timing of accrual	Close collaboration with medical and surgical oncologists, clinical trial nurse coordinators, and CHW	Early enrollment may empower patients, improve cultural and socio-demographic alignment, and increase trust with healthcare teams
Integration with PC teams	Embedded visits with medical and/or surgical oncology teams, telehealth visits, and use of patient-reported outcomes	Navigators connect patients and their caregivers to appropriate resources across multiple disciplines, which may improve addressing multiple PC domains (physical, psychological, social, spiritual, and cultural aspects of care)
Patient education sessions	Content can be administered in one or two sessions when necessary to meet patient needs. Education sessions can be administered either in-person or remotely	Navigators may improve common unmeasured confounding factors affecting patient outcomes, such as patient social support and level of engagement in their health. Education can be targeted to improve the likelihood of navigation success
Assuring receipt of needed services	Promote continuity of care with oncology care team by CHW establishing relationship early CHW to create resource binder, which is standard for position that includes hospice and PC resources	Navigators uniquely positioned to meet the needs of patients with unmet needs and help them better use outpatient resources. Unlike physicians and nursing staff, navigators are not limited by the traditional model of clinic-based care.
Assuring oncologist comfort with a new member of care team	Establish communication early with CHW regarding role and goals CHW to provide oncologist with insight beyond what oncologist would capture, which will affect context of care delivery	Navigators often have more time to spend with patients than physicians, physician assistants, and nurse practitioners do and are trained in skills that these care professionals do not possess. Navigators may increase efficiency and address more broad causes for cancer health disparities

Abbreviations: CHW, community health worker; PC, palliative care.

four times, and advance directive completion and PC referral were above historical standards at our cancer center.⁵⁵

With tactical training and support, the CHW provided components of PC that do not require a clinician, such as introducing ACP, sharing resources for hospice, and providing psychosocial support (Table 2). These processes are important for African American patients who report distrust with healthcare systems.^{56,57} The patient retention could perhaps be attributed to the CHW's ability to discuss sensitive content in a way more easily understood by patients and caregivers. In addition, the CHW spent an average of 40 minutes per session with patients, suggesting that the CHW had more time to engage issues and provisions of care not addressed in a routine clinic visit.

Our feasibility pilot study differs in important ways from ongoing developments addressing disparities in EOL care. Technology-based approaches are popular,^{58,59} but not pragmatic for patients who lack access or are uncomfortable with their use. A burgeoning implementation science literature and several randomized clinical trials support integration of CHWs or lay health workers to improve PC delivery in high-risk communities.^{17,19,25,39} Although these studies are promising, none focus on the African American community. Other interventions, such as culturally competent hospice educational materials,⁶⁰ videos to improve health literacy,⁶¹ and integration of peer support,⁶² fail to

address the multilevel issues, which drive healthcare disparities, unlike the present work.

This pilot study has several limitations. First, it was limited to a single center and single CHW with a predominately older population of African American descent, potentially limiting the generalizability to members of other racial minority groups and younger patients. External validity is limited as participants who enroll may differ from those who decline. Recruitment in an outpatient oncology clinic was successful, albeit slow to accrue given a high turnover of study coordinators (three research coordinators over 12 months for reasons unrelated to the study). Several strengths make this pilot study well-suited for practical use by health systems (Table 2). Our study was standardized in its approach to hiring, training, supervision, and workflow, while maintaining flexibility as deemed fit by the CHW. In addition, this study was conducted at the patient level and the 2-week communication skills curriculum resulted in an action plan that was carried out by the CHW.

In conclusion, this pilot study demonstrated feasibility and highlighted key areas for improving PC utilization and ACP discussions for African American patients with cancer. A larger multisite randomized trial is planned. The ultimate goal of health disparities research is to reduce or eliminate them by implementing models that consider the needs and preferences across various racial and ethnic groups. The efforts from this work continue to promote care equity for African Americans with advanced cancer.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Accountable for all aspects of the work: All authors

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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APPENDIX

TABLE A1. Differences Between Preintervention and Postintervention For Patient-Reported Outcomes

Survey	Mean (SD)	Median	P
NCCN physical and psychological distress (distress thermometer)			
Range = 0-10; 0 = no distress, 10 = extreme distress			
Baseline	5.5 (4.2)	5.5	.36
Month 3	4.7 (5.0)	3	
Center for epidemiological studies-depression			
Range = 0-60; higher score = more serious distress			
Baseline	42.2 (11.2)	45	.09
Month 3	33.6 (12.5)	31	
Edmonton Symptom Assessment System Revised Version			
Range = 0-100; higher score = more serious distress			
Baseline	33.8 (15.8)	36	.03
Month 3	18.8 (13.2)	16	
Functional Assessment of Chronic Illness Therapy—Palliative Care			
Range = 0-108; higher score = better well-being			
Baseline	106 (9.4)	109	.4
Month 3	104 (17.7)	110	

Abbreviations: NCCN, National Comprehensive Cancer Network; SD, standard deviation.