

Stakeholder Perspectives on the Use of Community Health Workers To Improve Palliative Care Use by African Americans with Cancer

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Abstract

Background: African Americans in the United States have worse end-of-life care and cancer outcomes than whites. Palliative care may improve this disparity. Community Health Workers may provide a means to improve palliative care disparities.

Methods: Semistructured in-depth interviews (five) and stakeholder focus groups (four) were conducted with cancer patients, caregivers, health care administrators, oncologists, and community health workers (CHWs). Patients were recruited through snowball sampling. Three raters coded interviews independently. Data were analyzed using interpretative phenomenological analysis.

Results: Seventy-one individuals were contacted to participate with 24 stakeholders (34%) participating in individual interviews or across 4 stakeholder engagements. Eleven constructs were identified and grouped in three broader themes: “hub of the wheel,” understanding palliative care, and patient–provider relationships. Participants felt that the role of a CHW should be central, bridging patients with their providers, information, and resources, including psychosocial support and advance care planning documents. They also placed an emphasis on the background of CHWs, saying individuals selected should be familiar with the history, culture, and norms of the communities from which they operate. Stakeholders reported that a CHW could activate a patient to contact their primary care physician or oncologist who may refer to or provide palliative care. Stakeholders reported that given the barriers to palliative care, a CHW could contribute to patient-centered multidisciplinary care while addressing palliative care domains with patients and families in a culturally sensitive manner.

Conclusion: Based on feedback from patients, caregivers, and providers, a culturally adapted CHW intervention may improve palliative care use for African American patients with advanced malignancies.

Keywords: community health worker; cultural competency; disparities

Introduction

THE U.S. HEALTH CARE SYSTEM is focused on delivery of high quality care, yet falls short of these goals in oncology and end-of-life care.^{1–4} Major gaps persist, contributing to disparities in outcomes among cancer patients. As a result, there is increased focus on value-based health care, which calls

for improved experience of care and better health.⁵ Palliative care has been proposed as a component of value-based care, yet is underutilized and initiated late in the course of disease.^{6,7}

Cultural values and social determinants of health influence health-related behaviors and decision making; this is particularly relevant for decision making among racial and ethnic minorities.⁸ Focused efforts are needed to understand

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and address disparities in minority populations' access to and use of palliative care, especially since increased health care expenditures have not resulted in decreased disparities in cancer outcomes.^{9,10} One such effort is the use of community health workers (CHWs), workers trained to educate patients on health conditions while helping them access health care and related social services and advocate for individual health needs.¹¹ There is little evidence on the effectiveness of CHWs to increase use of palliative care for African Americans. Herein, we describe the development of a lay navigation model to increase uptake of palliative care services by African American patients with advanced solid organ malignancies.

Methods

Stakeholder selection

Key informants were identified using the 7P stakeholder engagement framework.¹² We obtained input from: (1) providers (surgical and medical oncologists, palliative care and hospice clinicians, and CHWs); (2) patients and caregivers (African Americans with advanced solid organ malignancies); (3) payers (insurers and employers); (4) principal investigators; and (5) policy makers (hospital system administrators). Key informants were identified through snowball sampling and were invited to participate across four longitudinal focus groups or in a focused interview.

Data collection

Most stakeholders attended focus groups in person. A semistructured interview guide was developed to elicit participants' views and attitudes toward patient navigation and palliative care for African American patients with advanced malignancies. Members of the study team conducted all interviews and focus groups in a large, urban academic medical center. Interviews were digitally recorded and transcribed verbatim. The study was approved by the Johns Hopkins School of Medicine Institutional Review Board.

Analysis

Interpretative phenomenological analysis, a process which provides insights into individuals' described and lived experiences, was used for data analysis.^{13–15} Three reviewers performed independent coding of transcripts (F.M.J., J.H.N., and L.E.P.). The study team met following focus groups to discuss thematic codes and refine them into a focused coding structure. NVivo 11 (2017) was used to facilitate data management and organization. Thematic saturation was achieved over the course of the study.

Results

Participant characteristics

Twenty-four of the 71 stakeholders contacted (34%) participated in an individual interview or at least in 1 of 4 focus groups. Participants included 3 African American patients with advanced malignancies; 1 caregiver; 6 hospital administrators; 11 clinicians (5 hospice and palliative medicine and 7 oncologists); and 3 CHWs.

Themes and constructs

Analysis of coded transcripts revealed the following three major themes: "Hub of the Wheel," encompasses the role CHWs play connecting patients to resources; *Understanding Palliative Care*, encompasses ways CHWs can impact barriers to receipt of care; and *Patient-provider Relationship*, which describes the effect CHWs could have on the therapeutic alliance between patients and providers.

Hub of the wheel

Participants agreed that the role of CHWs should be central, bridging patients to providers and resources. Stakeholders framed *hub of the wheel* as building relationships within health care teams. CHWs described the CHW role as a bridge linking patients with medical, social, and material resources.

Resources. Stakeholders felt that a major role of CHWs should be linking patients to resources. Resources could include: (1) social and financial resources provided by health care systems and communities; (2) identification of hospice and palliative care resources (e.g., advance care planning documents, psychosocial support, and so on); and (3) patient activation to request and/or advocate for palliative care.

Patient and caregiver support. Patients reported psychosocial challenges upon receiving a diagnosis of advanced cancer and the resulting impact on family interactions. A CHW may therefore add value if they interfaced with the health care team and patient's family on the patient's behalf.

Psychosocial support. Stakeholders described the significance of psychosocial health in patients' care (Table 1). Yet many felt that clinicians lack the time and training to identify or address psychosocial needs. CHWs are trained in this aspect of support and may be well positioned to advocate for and activate patients to seek further help.

Spirituality. Stakeholders viewed spirituality as salient to patients in their cancer journey. Stakeholders envisioned a role of CHWs in affirming the spirituality of patients, while simultaneously guiding them through decision processes and beliefs about palliative care.

Understanding palliative care

Conflating hospice and palliative care. Stakeholders noted a major internal and external challenge to the rampant conflation of hospice and palliative care by patients and providers. Stakeholders felt that a trained CHW could provide clarity and counteract a lack of knowledge for patients and caregivers (Table 1).

Redundancy of messaging and information processing. Clinicians and CHWs stressed the importance of a titrated approach to messaging, in which discussions are customized and presented over time to allow uptake of the benefits and lessen barriers to palliative care. CHWs could discern patients' understanding and feelings regarding their

TABLE 1. CATEGORIES, SUBCATEGORIES, AND REPRESENTATIVE STAKEHOLDER COMMENTS

<i>Category</i>	<i>Subcategory</i>	<i>Stakeholder comments</i>
Hub of the wheel	Resources	“If it is transportation... If it is utility bills, you know, we can get that. If it is governmental identification thing—plenty of things that may cause them to not be eligible for these social resources... we can work on it. So I would say, doing a comprehensive assessment would surface all the social determinants.”
	Patient and caregiver support	“...whenever, you have the conversation [the key] is who’s doing the follow-up... it’s great if you have the conversation but then [patients and family members] go home and get together and talk about it. Guess what, you have a list of 20 questions? You’re not gonna call your physician back... But wouldn’t it be great if you had somebody that said, ‘I bet you have some questions...’”
	Psychosocial support	“... A lot of the time members get frustrated with care because it’s a little bit too much so they kind of give up in a sense and that’s where [patient navigators] come in. We advocate. We try to uplift them.”
	Spirituality	“Their services might be specifically important for African American patients, as something that a navigator should also include in their sort of job description.”
Systemic factors	Conflating hospice and palliative care	“So I’ve just defined palliative care but the patient, when you hear that word that buzz word—hospice, end of life—they’re like, ‘Woah! That must be really short,’ when I may be talking years.” “I think people just automatically assume that we’re giving up on them and that is sort of the end for them and don’t see it as much as a symptom management or some of the other holistic ways we can think about patient care. That it isn’t just the last two weeks of life.”
	Messaging redundancy and processing	“I’ve learned you have to sometimes say it four different ways cause it’s the third way that sort of makes sense.”
	Timing	“I think that is what you want as a system. So that everyone is ultimately getting the message that’s delivered, but in the language that they speak and at the time they’re ready to hear it.”
Patient–provider relationship	Activating and empowering	“So, I think making the palliative care [team] much more part of what’s normal and acceptable may help with the trust and acceptance... Because I think it definitely helps my patients... They have better symptom control, they feel more supported.” “But having those discussions, providing that care, that supportive measure—most doctors feel like they’re doing that.”
	Disconnect between patients and providers	“...African Americans in particular, are going to be more open to palliative because there are choices involved. Versus hospice—it’s one choice, and it’s giving up... That’s why you see the [difference in] utilization.” “Very educated lawyer...on hospice, very end of life, probably a week or two to live. They were devastated the first 48 hours because they said up until that point, they thought she was beating this.”
	Harming the therapeutic alliance	“...we aren’t trained to be good palliative care discussion leaders and we’re not trained to talk about end of life specifically and I think that a lot of physicians are afraid that in some ways that will harm the therapeutic alliance... it’s sort of a message that ‘I’ve given up on you,’ if I ask you about how you would like to die or how you would like the end of your life to be.” “Well I think a lot of people who have cancer are intimidated... they don’t want to ask questions to make them seem [stupid]... they’ll wait until they get home and try and find somebody who can help them.”
	Provider communication	“I think sometimes I need to work a little bit harder with my African American patients to have them trust me... so I think with these discussions, it has to be slow over time.” “I think another thing to focus on which may be incorporated into quality of life is the whole financial issue... there’s a lot of talk about financial toxicity, not only toxicity from the treatments... there’s a drive for oncologists to discuss that more with their patients.”

symptoms and prognosis and articulate the benefits of palliative care in a nonthreatening way.

Timing. Stakeholders described the time-sensitive nature of introducing palliative care at diagnosis. Participants reported that CHWs could assist in fostering discussion with

oncologist about palliative care and provide greater understanding of community resources earlier (Table 1).

Patient–provider relationship

Activating and empowering. Patients and family participants stated that they are regularly overwhelmed and

exhausted by the complexity and constancy of cancer treatment. By activating and empowering patients and caregivers to discuss palliative care options with oncologists, CHWs may strengthen the therapeutic relationship and improve the quality of care (Table 1).

Disconnect between patients and providers. Myriad sociocultural and role-related factors contribute to disparate understanding of treatment plans, care preferences, and prognosis. In addition, there can be a disconnect in the relationship, which stems from the history between African Americans and the medical community. Therefore stakeholders reported the importance of CHW familiarity with the community to maximize the buy-in of patients (Table 1).

Provider communication. Stakeholders felt that CHWs could cultivate a framework for culturally competent communication. CHWs could elucidate the social determinants of health faced by the patient and their beliefs about palliative

care. Such insights into patient preferences could help providers deliver goal concordant care (Table 1).

Discussion

We report on a stakeholder engaged process to assess views regarding the use of CHWs to facilitate uptake of palliative care. Our results suggest that CHWs may be a useful addition to cancer care teams to advocate for and activate African American patients with advanced malignancies and their caregivers to seek palliative care. CHWs may be trained to augment the limitations within care teams of cultural competence and time and provide components of palliative care which do not require a clinician, including advance care planning, resources for hospice, and psychosocial support. We identified several relevant deliverables that may require greater focus during development and will guide intervention assessment and implementation (Table 2).

Stakeholders universally saw benefit in increasing use of hospice and palliative care through ongoing titrated discussions

TABLE 2. DELIVERABLES FOLLOWING STAKEHOLDER ENGAGEMENT

<i>Stakeholder</i>	<i>Category</i>	<i>Pre-engagement</i>	<i>Postengagement</i>
Navigator	Caseload	60–80 clients with varying levels of needs	<30 clients breadth of service a function of caseload so decrease caseload to accommodate
	Goals	Work with patients early, in-depth inventory of needs (medical & social), provide support	No change
	EMR	Training and use unnecessary	Training and use vital for communication with patient and health care team
	Medical background Support	None necessary	No change
	Training	Access to training and counseling to avoid burnout	Training important and ability to collocate with palliative care team for real time debriefing and burnout avoidance
Oncology clinician	Navigator role	Disparities Cultural competency Palliative and end-of-life care principles EMRs	Disparities Cultural competency Palliative and end-of-life care principles EMRs Communication Linking of community and palliative care resources Motivational interviewing
Palliative care clinician	Navigator role	Link to health care team beyond diagnosis	Link to health care team beyond diagnosis Assistance with advance care planning Resources for social, financial, palliative care, and end-of-life care support
Administration	Navigator role	Provide comfort with palliative care domains	Provide comfort with palliative care domains (psychosocial support, advance care planning, etc.) Activate and motivation to seek palliative care
Patients	Navigator role	Improve cost of care through decreased utilization of resources	Improve quality of care Improve patient satisfaction Improve use of palliative care
Patients	Navigator role	Motivation and activation	Motivation and activation Nonthreatening, nonmedical motivator Confidante Comfort with spiritual discussions

EMR, electronic medical record.

between patients and CHWs. This template was recently used by lay navigators, leading to fewer hospitalizations and intensive care unit admissions at the end of life in cancer patients.¹⁶ Activating patients to discuss palliative care domains may also facilitate the clinician's role in palliative and end-of-life care, decrease anxieties, and empower patients to make more informed decisions regarding their care.

These findings may extend the scope of practice of CHWs. Recent literature suggests that this can be done successfully. Fischer et al. implemented a culturally informed patient navigator intervention for Latinos with advanced medical illness.¹⁷ Similarly, lay navigators have been utilized within health systems and cancer centers to improve use of advance care planning and care across the continuum of cancer from diagnosis through end of life.^{16,18} Alternatively, some authors have reported barriers to lay navigators' effectiveness supporting people with advanced cancer during follow-up meetings.¹⁹ This literature was informative to our process and has grounded the refinement of CHW roles and training.

Our study has several limitations. First, challenges arose with recruiting advance-stage cancer patients to participate. Due to the nature of their illness, patients experienced acute illness or death, limiting their motivation or ability to participate. Second, palliative care is a complex, often misunderstood topic. To ensure everyone used the term the same way, a portion of each focus group was used to disseminate a common definition.

In this study, we assessed the views of African American patients with advanced cancer, their caregivers, and providers regarding how CHWs might be utilized to improve uptake of palliative care. Our group has developed a training program for CHWs and is in the process of piloting the intervention. By grounding our work in stakeholder input with outcomes and process relevant to them, we hope this intervention will be more relevant, sustainable, and a basis for expanded utilization of palliative care.

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