



African American patient and caregiver attitudes and perceptions of community health workers as lay patient navigators in palliative care

Olivia Monton^{1,2}, Shannon Fuller³, Amn Siddiqi¹, Alison P. Woods^{1,4}, Taleaa Masroor¹, Robert Joyner⁵, Ronit Elk⁶, Jill Owczarzak³, Fabian M. Johnston⁷

¹Department of Surgery, Johns Hopkins University School of Medicine, Baltimore, MD, USA; ²Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; ³Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; ⁴Department of Surgery, Beth Israel Deaconess Medical Center, Boston, MA, USA; ⁵TidalHealth Richard A. Henson Research Institute, Salisbury, MD, USA; ⁶University of Alabama at Birmingham Department of Medicine, Birmingham, AL, USA; ⁷Division of Gastrointestinal Surgical Oncology, Department of Surgery, Johns Hopkins School of Medicine, Baltimore, MD, USA

Contributions: (I) Conception and design: O Monton, S Fuller, A Siddiqi, AP Woods, R Joyner, R Elk, J Owczarzak, FM Johnston; (II) Administrative support: O Monton, A Siddiqi, AP Woods, T Masroor; (III) Provision of study materials or patients: R Joyner, R Elk, FM Johnston; (IV) Collection and assembly of data: S Fuller, A Siddiqi, J Owczarzak; (V) Data analysis and interpretation: O Monton, S Fuller, J Owczarzak, FM Johnston; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

Correspondence to: Fabian M. Johnston, MD, MHS, FACS, FSSO. Associate Professor of Surgery and Oncology, Chief, Division of Gastrointestinal Surgical Oncology, Department of Surgery, Johns Hopkins School of Medicine, 600 N. Wolfe Street, Blalock 606, Baltimore, MD 21287, USA. Email: fjohnst4@jhmi.edu.

Background: Concurrent palliative care for patients with advanced cancer has been shown to reduce physical and psychological symptoms, and improve the quality of life of patients with advanced cancer. Underutilization of palliative care services, especially among African American patients with advanced cancer, remains an important public health problem. To address this gap, we developed a community health worker (CHW) palliative care intervention for African American patients with advanced cancer, which is being formally assessed through an ongoing effectiveness-implementation trial (NCT05407844). As part of the preparatory phase of this study, we conducted qualitative interviews with African American patients with advanced cancer and their caregivers. The objective of this analysis was to explore patient and caregiver attitudes and perceptions of the CHW palliative care intervention to support African American patients with advanced cancer in accessing palliative care.

Methods: We used purposive sampling to identify African American patients with advanced cancer and their informal caregivers from clinic lists and through referring oncologists. We conducted six individual and group semi-structured interviews with patients and caregivers between November 2022 and April 2023 at three enrollment sites: Johns Hopkins Hospital, TidalHealth Peninsula Regional, and University of Alabama at Birmingham Hospital. The interview guide was informed by the Consolidated Framework for Implementation Research, with a focus on the Innovation and Inner Setting domains. We used the framework method for thematic analysis.

Results: Overall, there was a lack of awareness and understanding of palliative care, due primarily to limited experiences with palliative care services among study participants. Despite this lack of familiarity, participants recognized the potential benefits of palliative care for patients with advanced cancer. All study participants were enthusiastic about the concept of patient navigation and the CHW palliative care intervention, with CHWs as lay patient navigators in palliative care. When reflecting on their own experiences, patients and their caregivers identified several areas where CHWs may have supported their cancer care, such as care coordination. Study participants viewed the CHW palliative care intervention as fulfilling a need within the African American community. Participants also made intervention delivery recommendations related to CHW characteristics, training and integration, and communication.

Conclusions: This study provides evidence for the acceptability of a CHW palliative care intervention for African American patients with advanced cancer and their caregivers. The findings of this study have led to intervention refinement, which will enhance implementation, delivery, and sustainability of the intervention.

Keywords: Palliative care; patient navigation; community health worker (CHW); health disparities

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Introduction

The American Society of Clinical Oncology recommends early integration of palliative care for all patients with advanced cancer (1). Components of palliative care include formal assessment of physical symptoms and psychosocial health, associated management, education related to prognosis and treatment options, and discussions about goals of care and advance care planning, all delivered by an interdisciplinary team (1). Concurrent palliative care has been shown to reduce physical and psychological symptoms, and improve the quality of life of patients with advanced cancer (2-6). Palliative care capabilities are increasing in the United States, with approximately 83% of hospitals with 50 beds or more reporting a palliative

care team in 2020 (7,8). Despite its wide acceptance and the increasing capacity for palliative care in the United States, underutilization of palliative care services among patients with advanced cancer remains an important challenge (9-11). Furthermore, racial disparities in the access to palliative care services exist, with African American patients experiencing disproportionately lower rates of palliative care utilization compared to White patients (12-14). As a result, African American patients are less likely than White patients to undergo advance care planning and receive goal concordant care at the end of life (15,16). Unfortunately, palliative care literature often fails to incorporate implementation science principles and frameworks into study design and conduct, which limits the translation and long-term adoption of palliative care interventions in clinical practice settings and has contributed to an evidence to practice gap in palliative care (16-18).

To address this gap, we developed a community health worker (CHW) palliative care intervention for African American patients with advanced cancer and their caregivers, which is currently being tested through a randomized, pragmatic, hybrid type 1 effectiveness-implementation trial at three cancer centers across the United States, Johns Hopkins Hospital (JHH), TidalHealth Peninsula Regional (TH), and University of Alabama at Birmingham Hospital (UAB Hospital) (NCT05407844) (19-23). CHWs are front-line public health workers that typically work in the community setting and help patients from marginalized communities by addressing barriers in access to healthcare services and social determinants of health (SDOH) (24). Their deployment in various practice settings has proven effective in overcoming healthcare barriers across a spectrum of diseases (25). Moreover, CHWs have been incorporated into research settings to facilitate participation and navigation in clinical trials (26).

As part of the preparatory phase of the clinical trial, CHWs were onboarded at each enrollment site and underwent comprehensive training on palliative care,

Highlight box

Key findings

- Participants had limited understanding of and experience with the intervention components (palliative care and patient navigation), however, perceived both palliative care and patient navigation as beneficial to African American patients with advanced cancer and their caregivers.
- Participants viewed the community health worker (CHW) palliative care intervention as fulfilling a specific need within the African American community.
- Participants made recommendations related to CHW characteristics, training and integration, and communication.

What is known and what is new?

- African American patients have lower palliative care utilization rates compared to White patients.
- This study provides evidence for the acceptability and potential benefit of a CHW palliative care intervention for African American patients with advanced cancer and their caregivers.

What is the implication, and what should change now?

- The findings of this study have led to intervention refinement, which will enhance implementation, delivery, and sustainability of the intervention.

Table 1 Core CHW roles included in the CHW palliative care intervention. Adapted from The Community Health Worker Core Consensus Project (28)

Core CHW roles	Intervention-specific role description
Cultural mediation among individuals and health and social service systems	CHWs will provide cultural mediation, bridging any cultural gaps between patients and the institutions providing them with health and social services
Providing culturally appropriate health education and information	CHWs will deliver health education tailored to the cultural background of each patient and caregiver. This will include educating them about the role and benefits of palliative care in a culturally sensitive manner
Care coordination and system navigation	CHWs will assist patients in navigating the healthcare system to ensure they have timely access to palliative care resources and support. This will involve coordinating care between different healthcare providers and services
Providing coaching and social support	CHWs will coach patients and caregivers on establishing goals of care and initiating advance care planning (ACP) discussions. Additionally, they will offer social support and encouragement throughout the care journey
Advocating for individuals	CHWs will advocate for patients within the healthcare system, ensuring their needs and preferences are met. They will also advocate for the provision of palliative care services that align with the cultural and individual needs of patients and caregivers
Building individual capacity	CHWs will empower patients and caregivers to build their capacity for self-care, make complex treatment decisions, and engage in advance care planning
Implementing individual assessments	CHWs will conduct comprehensive assessments of patients and their caregivers periodically using the Protocol for Responding to & Assessing Patients' Assets, Risks & Experiences (PRAPARE) screening tool to identify their needs and establish personalized care plans (27)
Participating in evaluation and research	CHWs will participate in evaluation and research by delivering the intervention and serving as a member of the research team

CHW, community health worker.

oncology, patient navigation, and health disparities (19). This training aimed to equip CHWs with the necessary knowledge and skills to effectively support African American patients with advanced cancer and caregivers, by addressing individual barriers to healthcare, SDOH, and palliative care needs (19). The intervention begins with a baseline assessment of barriers to healthcare and SDOH using an adapted version of the Protocol for Responding to & Assessing Patients' Assets, Risks & Experiences (PRAPARE) screening tool (27). The CHW then provides tailored and individualized support to patients and their families, with periodic assessments throughout the intervention, on an as needed basis. The intervention is multifaceted and is centered around The Community Health Worker Core Consensus Project's CHW Roles, adapted to address the palliative care needs of African American patients with advanced cancer and their caregivers (20,22,28). Components of the Core CHW Roles included in the intervention are: (I) cultural mediation among individuals and health and social service systems; (II) providing

culturally appropriate health education and information; (III) care coordination and system navigation; (IV) providing coaching and social support; (V) advocating for individuals; (VI) building individual capacity; (VII) implementing individual assessments; and (VIII) participating in evaluation and research. Intervention-specific role descriptions are outlined in *Table 1* (28). This intervention is geared towards individuals (patients and their caregivers), and as such, does not directly target communities broadly. One central component of the intervention is patient navigation, a patient-centric healthcare service delivery model that promotes the timely movement of patients through the healthcare system, with the goal of eliminating barriers to care across the care continuum (29). Patient navigation programs differ in terms of staffing and services provided, and may be delivered by health care professionals or lay workers (30). In the context of cancer care, this can include helping patients navigate the healthcare system from the time of cancer diagnosis, through testing, chemotherapy, radiation therapy, surgery, survivorship, or end-of-life

Table 2 Composition of the study interviews

Interview number	Composition
1	2 patients, 1 patient-caregiver dyad
2	2 patient-caregiver dyads
3	1 patient, 1 patient-caregiver dyad
4	1 patient-caregiver dyad
5	1 patient
6	2 patients

care. It is important to note that CHWs are referred to by more than 30 terms, including patient navigators and lay navigators (25,31). For the purposes of this study, patient navigation should be understood as a core component of the CHW palliative care intervention.

The objective of this analysis was to explore patient and caregiver attitudes and perceptions of the CHW palliative care intervention to support African American patients with advanced cancer in accessing palliative care. More specifically, we aimed to characterize perceptions related to the intervention and intervention components, palliative care and patient navigation. We present this article in accordance with the COREQ reporting checklist (32) (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-602/rc>).

Methods

We conducted six individual and group semi-structured interviews with African American patients with advanced cancer and their caregivers. The interview compositions are outlined in *Table 2*. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study procedures were approved by the Johns Hopkins Medicine Institutional Review Board (No. IRB00283002), which serves as a single-site IRB for this study, with reliance agreements in place with TidalHealth Peninsula Regional and University of Alabama at Birmingham. Informed consent was obtained from all individual participants.

Study setting

Patients and caregivers were recruited from three enrollment sites: JHH, TH, and UAB Hospital, between November 2022 and April 2023. The enrollment sites represent three different settings, including an urban

setting in Baltimore, Maryland, a rural setting in Salisbury, Maryland, and an urban area with surrounding suburban and rural communities in Birmingham, Alabama.

Participants and recruitment

We used purposive sampling to identify African American patients with advanced cancer and their informal caregivers at the three participating sites. An informal caregiver is someone who provides unpaid care to an individual with whom they have a personal relationship, for example, a family member or friend (33). Adult patients were eligible if they self-identified as African American, had a personal history of advanced solid organ malignancy (American Joint Committee on Cancer stages III and IV), and were English speaking. Adult caregivers were eligible if they provided care to an eligible patient participant and were English speaking. Research coordinators contacted eligible patients through referring oncologists (medical, radiation, surgical) via telephone or in person to discuss the study and obtain informed consent. Interested caregivers were recruited through consented patient participants and similarly went through an informed consent process. Not identifying a caregiver who was interested in participating did not preclude patient participation.

Research team

The interviews were conducted by three authors (J.O., S.F., A.S.). Two authors (J.O., S.F.) are experienced qualitative researchers and served as lead moderators. The third facilitator (A.S.) had undergone training in qualitative interviewing. No facilitators had pre-established relationships with study participants prior to recruitment.

Interview guide

The semi-structured interview guide was created by members of the research team (O.M., A.W., A.S., S.F., J.O., F.J.) through an iterative and collaborative process. The guide was informed by the Consolidated Framework for Implementation Research (CFIR), a well-established implementation science framework organized by five domains to capture multi-level barriers and facilitators to intervention implementation (34). Damschroder *et al.* [2009] advocate for the selection and use of CFIR domains and constructs that best align with the research objectives (35). Therefore, for this project, we focused on the *Innovation*

and *Inner Setting* domains, as we believed these would provide the most insight into participants' attitudes and perceptions regarding the intervention and its components. Within the *Innovation* domain, we utilized the *innovation design* construct to explore perceptions of the intervention and its components (palliative care and patient navigation). Additionally, we used the *relative advantage* construct to understand how the intervention might address gaps in current practices. Furthermore, the *culture* construct within the *Inner Setting* domain was used to understand how participants' values and beliefs shaped their perceptions of the intervention. The guide was divided into three major content areas: palliative care, patient navigation, and the CHW palliative care intervention, in order to spend sufficient time on different components of the intervention. The interview guide was developed for the focus group setting and was adapted by the lead moderators for individual and group interviews.

Interview procedures

Interviews were scheduled at mutually agreeable times and were conducted virtually via the Johns Hopkins Zoom platform (Zoom Video Communications, Inc., San Jose, CA, USA), with two facilitators and the participants. All interviews were conducted in a private setting and lasted approximately 90 minutes. The interviews were audio-recorded, transcribed, and checked for accuracy by a member of the research team. Following completion, all participants received a \$50 gift card. We explained that participation was voluntary and reinforced that the contents of each interview would be kept confidential. Further, for interviews conducted in the group setting, we asked that all responses made by study participants be kept confidential.

Based on our semi-structured interview guide, we started each session by presenting content areas (palliative care and patient navigation) to participants and followed-up with questions related to their awareness and understanding of each concept. We subsequently provided participants with detailed explanations of each concept and explored their perceptions and attitudes, providing clarification and outlining examples, as required. Finally, we presented the CHW palliative care intervention and explored participants' attitudes about the intervention.

Analysis

The interview transcripts were imported into the MAXQDA software (VERBI Software, Berlin, Germany). We used

the framework method described by Gale *et al.* [2013] to facilitate thematic analysis (36). Two authors (O.M., S.F.) engaged in a process of familiarization with the data. They subsequently coded the data using a targeted approach to coding, based on a priori codes that were developed as part of an analysis of 25 key informant interviews with professional stakeholders from the three enrollment sites, which similarly sought to establish the attitudes and perceptions of the intervention and intervention components, reported separately. Original codebook development was abductive, balancing deductive codes generated from the interview guide, with inductive codes that emerged from the data (37). For this analysis, two authors (O.M., S.F.) used this a priori codebook, and added inductive codes to capture additional nuances that emerged in the interviews with patients and caregivers. The codebook was then refined following comparison among two analysts (O.M., S.F.). Discrepancies identified throughout the process were reviewed and resolved by the same two analysts. Each transcript was then independently coded by the two analysts. One author (O.M.) then created an analysis table to summarize the coded segments and generate preliminary domains and themes across all three enrollment sites. All codes related to awareness, understanding, attitudes, and perceptions of palliative care, patient navigation, and the CHW palliative care intervention were included. A sample codebook with select codes and definitions by content area is available in [Table S1](#). The two authors (O.M., S.F.) then refined the domains and themes through comparisons. Site-specific and subgroup analyses were not performed.

Results

Participant characteristics

We approached a total of 38 potential participants (28 patients and 10 caregivers) who met our eligibility criteria, of whom 16 participants (11 patients and 5 caregivers) agreed to participate and were enrolled in the study. Among the patient participants, the median age was 69 years (40–79 years), and the majority (73%) were female. Caregivers were either spouses (40%), children (40%), or siblings (20%). Additional patient characteristics can be found in [Table 3](#).

Thematic analysis

We organized our findings into 3 domains, including perceived barriers to palliative care, anticipated benefits,

Table 3 Baseline characteristics by group

Characteristics	Patients (n=11)	Caregivers (n=5)
Study site, n [%]		
JHH	4 [36]	1 [20]
TH	4 [36]	1 [20]
UAB Hospital	3 [27]	3 [60]
Age (years), median [range]	69 [40–79]	43 [38–80]
Gender, n [%]		
Female	8 [73]	3 [60]
Male	3 [27]	2 [40]
Insurance status, n [%]		
Medicare	5 [46]	N/A
Medicaid	3 [27]	
Private insurance	3 [27]	
Primary site, n [%]		
Breast	2 [18]	N/A
Prostate	1 [9]	
Lung	1 [9]	
Gastrointestinal	7 [64]	
Relationship to patient, n [%]		
Spouse	N/A	2 [40]
Child		2 [40]
Sibling		1 [20]

JHH, Johns Hopkins Hospital; TH, TidalHealth Peninsula Regional; UAB Hospital, University of Alabama at Birmingham Hospital; N/A, not applicable.

and participant recommendations.

Perceived barriers to palliative care

Lack of understanding

We started by asking participants what their understanding of palliative care was, then developed a shared understanding of palliative care by providing a definition and discussing the concept in detail. We then probed for experiences with palliative care services. Most participants had a limited understanding of palliative care and its service offerings. Of the 16 participants, only two patient-caregiver dyads had prior experience with palliative care, which contributed to their understanding of the term. The 12 remaining participants did not recall being offered anything that

sounded like palliative care at any point throughout their cancer care continuum; it was not something they knew to ask their doctors about because it was not talked about or discussed with healthcare providers or their peers. Of the participants with no prior experience, most had a limited understanding of palliative care. After establishing a shared definition, we explored potential challenges contributing to the lack of understanding. Participants highlighted the complexity of the term palliative, which was described as “daunting” and was felt to contribute to a lack of understanding and engagement in palliative care services. Conflation with hospice care was described as another factor contributing to misunderstanding. Participants expressed that people may associate the term with end-of-life care, which could deter engagement:

- ❖ I think that many people perceive palliative care similar to hospice in that it’s for end of life or your most dire situations. So, I can’t speak for other people, but I can say that I would perceive that not many people receive palliative care that need it. (UAB Hospital, Patient)

Perceived cost

Participants expressed that the perceived financial burden of palliative care services may also contribute to a lack of engagement. This stemmed from uncertainty as to whether palliative care services were covered by insurance. There were concerns about how patients who are on fixed income would be able to access these services. One participant stated that African American patients on a fixed income may assume that palliative care services are not covered by insurance, which could lead these patients to worry about paying for these services:

- ❖ And in feeling like, you know, a Black person probably saying, “Hey, this is all I can get.” [...] I mean, because they’re feeling like they’re on this income and [thinking] do I have to worry about paying for this service. (JHH, Caregiver)

Another patient participant in this interview reiterated that worry about paying for healthcare services was, “a very big thing in the African American community.” (JHH, Patient)

Anticipated benefits

Palliative care

Upon establishing a shared definition of palliative care, all participants expressed that palliative care could be beneficial to patients with advanced cancer and their caregivers. The few participants who had prior palliative care experience

described the palliative care team as addressing both physical and psychosocial care needs, as one caregiver from TH summarized:

- ❖ You know, they touch on a little bit of everything because they touch on her emotions. [...] It's not just medication, but I think it's a psychological support thing, too. I think their goal is to reach out in all areas more than just medication. (TH, Caregiver)

When asked about the optimal timing of a palliative care consultation, participants agreed that palliative care should be first introduced to all patients with advanced cancer at the time of diagnosis, with one patient advocating for its reintroduction at multiple time points throughout the cancer care continuum:

- ❖ I also think that it would be good to reinforce that throughout periods of treatment as well. Because I've learned that we are so overwhelmed when we first get diagnosed and it's good to have reminders along the way. (UAB Hospital, Patient)

Interview participants felt that providing a detailed explanation of palliative care and associated educational materials at the time of diagnosis could help patients and caregivers understand the benefits of palliative care and incorporate it into their treatment plan.

Patient navigation

No participants had any prior experience with patient navigation and as a result had limited understanding of patient navigation as a concept. All patients and caregivers reacted positively to the description of patient navigation. They reflected on their own experiences with cancer care and most expressed that a patient navigator would have been very helpful for them. They conveyed that a patient navigator may be especially valuable for patients who lack a support system. Participants identified many potential supportive roles that a patient navigator could play for patients with advanced cancer based on their own experiences. First, they thought that a patient navigator could help patients coordinate care. This role could include assisting patients with scheduling clinical appointments, coordinating transport needs, and keeping patients organized. One patient stated:

- ❖ It could help the person be more organized. When you're going through an illness like this, you have so much on your mind; thinking about the illness itself and how it's making you feel. [...] Your mind isn't very clear. (TH, Patient)

Another potential benefit expressed was that patient navigators may also enhance care consistency. Participants

articulated that navigators could become the key contact person for patients and their caregivers, serving as the link between the patient and the clinical team, which may also help to establish a consistent care plan. Patient navigators were perceived as patient advocates. Given their understanding of patients' unique care needs, navigators were felt to represent the patient voice within the clinical team. Participants stated that in their role, patient navigators could also provide emotional and social support to patients, and may even become a friend to the patient; someone they would feel comfortable reaching out to in times of need, who would understand their needs and be in contact with the clinical team, when necessary. One caregiver stated that being able to contact a patient navigator in times of need may even help patients avoid unnecessary emergency room visits and hospital admissions. A JHH patient recounted a personal experience where she was in crisis and could not reach her doctor, and reflected on how a patient navigator may have helped her in this situation:

- ❖ Respecting everything that [my doctor] was doing, that would hurt my feelings, because here I am sick as a dog at home, I don't want to go back into the Emergency Department, and I can't reach anybody at the hospital who knows my case. (JHH, Patient)

CHW intervention

When a detailed explanation of the intervention was provided, all patients and caregivers were enthusiastic about the intervention and its potential value. All study participants endorsed that having a CHW from the same community was important. They expressed that being able to relate to their CHW would help them establish a relationship built on trust. One participant stated:

- ❖ You know your people. If you know the people in the community that have faith or trust, then because of what they've seen and what they've seen you go through, they can relate to that much easier than a stranger. (TH, Patient)

In response, a caregiver stated:

- ❖ You're right. You're certainly right. That's why I said a little early on if there's somebody that you know that you can trust and you got a good rapport with, you're absolutely right, rather than a stranger. (TH, Caregiver)

Furthermore, participants felt that the intervention was fulfilling a specific need within the African American community. This was based on participants' perceptions that African Americans may not receive the same level of care as White patients. One caregiver stated:

- ❖ I mean, I don't want to offend, but I feel like White people get more care and information than Blacks. And I feel like this is very important what you are doing. It's very much needed. I mean, the Black community, we have a lot of health issues as well, but we're low on the totem pole. (JHH, Caregiver)

Participant recommendations

Desired qualities of a CHW

Participants highlighted several personal characteristics that would make a good patient navigator. First, that they should be good at interacting with people. One patient expressed it as:

- ❖ They've got to be a people person. They've got to know how to deal with people. (JHH, Patient).

Kindness, patience, and a positive attitude were also recognized as important attributes. Participants thought that CHWs should be compassionate and care about the patients they are serving. One patient expressed that in times of crisis, patient navigators may be required to go above and beyond their job description to assist patients in times of need, even if this happened to be outside of normal working hours.

CHW training and integration

Participants highlighted the importance of CHWs possessing a detailed understanding of their roles and responsibilities, and undergoing training to ensure competence. Knowledge of patients' medical history, active medical issues, and insurance coverage were described as priorities. A patient from JHH emphasized the importance of knowledge:

- ❖ And knowledge, they've got to have knowledge. Give me that knowledge. Don't come to me acting dumb because I will tell you, okay, you need to go. (JHH, Patient).

Another priority was for navigators to be well-versed in the various types of insurance plans to be able to counsel patients on what services are covered. Finally, patients and caregivers conveyed the importance of CHWs being well integrated into the interprofessional team, and emphasized the importance of CHWs having established professional relationships with all team members.

Initial introduction and communication

Respondents felt that the ideal time to introduce patients to their CHW was at the time of cancer diagnosis. Educating patients and their caregivers on the role of the CHW was described as an important first step in connecting patients and CHWs. One patient said:

- ❖ Make sure you explain it and what it entails. I think that's the most important part about it. (UAB Hospital, Patient).

It was considered essential to afford patients with the opportunity to meet their CHWs and assess overall fit and compatibility before establishing a working relationship. One participant stated that this was a prerequisite to building trust:

- ❖ You're going to have to have some conversation with them and feel them out before you can know whether you trust someone or not. (TH, Caregiver).

Participants felt that initial contact with the CHW should be made through telephone communication, with a subsequent in-person follow-up based on the patient's comfort level. They also stressed the importance of aligning ongoing methods of communication (i.e., phone or in-person) with patient preferences.

Discussion

The present study builds upon a collection of studies demonstrating the potential benefit of a CHW palliative care intervention to decrease disparities in the access to and utilization of palliative care services among African American patients with advanced cancer and their caregivers (21-23). This study highlights African American patient and caregiver attitudes and perceptions of the CHW palliative care intervention, in addition to intervention components, palliative care and patient navigation. There was a general lack of awareness and understanding of palliative care, stemming from limited experience with palliative care services among study participants. Despite this lack of familiarity, participants recognized palliative care as being potentially beneficial for patients with advanced cancer. The concept of patient navigation and the CHW palliative care intervention were readily endorsed by all study participants. Both patients and their caregivers reflected on their own experiences with cancer care and identified many areas where CHWs may have helped with various aspects of their care, such as care coordination, serving as the link to the clinical care team, and addressing psychosocial needs. Study participants also made intervention delivery recommendations, including recommendations related to CHW characteristics, training and integration, and communication. These recommendations have reinforced elements that are already included in the planned intervention (*Figure 1*).

One core component of the intervention is educating

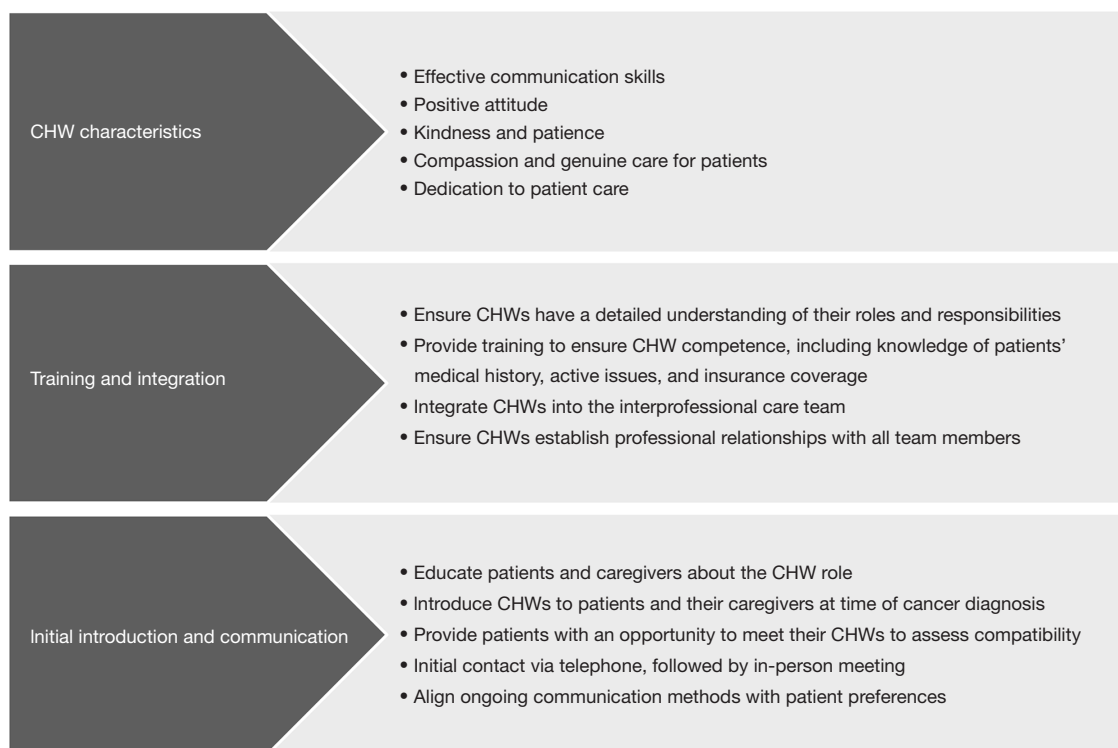


Figure 1 Participant recommendations. CHW, community health worker.

patients and their caregivers on palliative care, its service offerings, and potential benefits. Most participants did not recall being offered anything like palliative care during their cancer care. Provider- and patient-level factors likely contributed to this. From the provider perspective, research has demonstrated that palliative care referral practices vary widely within oncology, where oncologists may avoid referral due to perceptions of palliative care as being incompatible with cancer therapy, a view that providing palliative care is a part of the oncologist's role, and a lack of knowledge about available services (38). From the patient perspective, a few study participants attested to feeling very overwhelmed at the time of diagnosis and not being able to recall the information that was provided by their doctors. One study that examined information seeking behaviours following cancer diagnosis referred to the initial phase immediately after diagnosis as “blocking it out”, where due to the stress associated with the diagnosis, patients have a decreased ability to absorb information and articulate their needs (38). This is compounded by poor information recall overall, which has been found to be as low as 23% within oncology settings (39). This has implications for patients being able to absorb and recall information provided on

palliative care early on in their disease trajectory. Moreover, participants highlighted the perceived cost of palliative care services as a potential barrier, particularly among African American patients. Research suggests that racial disparities further contribute to barriers in accessing palliative care (40). Older adults from minority populations, particularly African Americans, often lack knowledge about palliative care, and spiritual and religious beliefs within these communities may conflict with the principles of palliative care (41-45). Additionally, historical injustices and ongoing healthcare disparities can engender mistrust, leading to concerns about the perception of forgoing curative treatments when initiating palliative care (46,47). These complex factors pose significant challenges in promoting the utilization of palliative care services among African American patients.

Through discussions with patients and their caregivers, it became apparent that patients may have high expectations of their CHWs in terms of personal characteristics, knowledge and training, availability, and serving as a link between the patient and the healthcare team. For example, one patient emphasized that CHWs should be dedicated and available to help patients in times of need. These heightened expectations suggest that the role may exert

considerable strain on CHWs and potentially expose them to the risk of burnout. While burnout is being increasingly studied among medical and mental health providers, there is limited research on the health and well-being of CHWs in the United States (48). Despite this, a few studies have underscored the importance of addressing the health and well-being of CHWs. In a recent study, Ibe *et al.* [2023] explored the experiences of CHWs in Baltimore, Maryland. The authors highlighted the fact that belonging to marginalized communities equips CHWs with knowledge and expertise in delivering interventions that address their clients' social risk factors; however, this connection to the community also exposes CHWs to potential psychosocial, physical, and institutional harms (24). CHWs in this study reported feelings of burnout and hopelessness, and expressed that their role as a CHW sometimes took a toll on their mental health and well-being. This deep emotional labor and connection to the community can have both positive and negative implications for CHWs (48,49). Another study distinguishes between two types of CHW emotional labor, surface-level emotional labor and deep-level emotional labor. The authors found that while surface-level emotional labour is associated with higher job satisfaction, with burnout partially mediating this relationship, deep-level emotional labour is associated with lower job satisfaction, a relationship which is fully mediated by burnout (50). Further, an intervention centered around palliative care for patients with advanced cancer may have a greater emotional toll on CHWs than interventions focused on less serious illness (51). It is therefore essential to support CHWs in their role to ensure their health and well-being is prioritized.

Based on these findings, we have ensured that all CHWs that will be implementing the intervention are well-educated on all aspects of palliative care services, including the services provided, the potential benefits to patients and their families, how the services differ from other services (such as hospice care), and insurance coverage. CHWs have also been instructed to discuss these concepts with patients frequently throughout the care continuum, to facilitate understanding and encourage engagement and utilization of palliative care services at multiple time points. Further, we have implemented strategies as part of the intervention to promote the health and well-being of study CHWs throughout the entirety of the study period and prevent burnout. These strategies include appropriate compensation, ongoing peer-support with an experienced CHW at our central study site, and access to psychosocial

resources. These lessons learned can serve as valuable guidance for other CHW programs focused on addressing healthcare disparities among patients with serious illness.

The DeCIDE PC study is a multifaceted implementation science research study with several aims. The present study was conducted as part of Aim 1 of this initiative, with the goal of understanding patient and caregiver attitudes towards the intervention and its components. One significant limitation of our study pertained to the sample size. Although many patients indicated their willingness to participate during initial contact, subsequent attempts at reaching them were frequently unsuccessful. For some patients, this was due to hospital admission for acute illness. We anticipate that other patients who declined to engage further may not have felt well enough to participate or may not have had the bandwidth, given the physical and psychosocial challenges associated with an advanced cancer diagnosis. Caregivers, who were recruited through patients, also appeared to be reluctant to participate, which contributed to the low number of caregivers enrolled in this study. One potential barrier to participation for caregivers may be a lack of time and availability, due to the demands of cancer caregiving in addition to their other responsibilities (52). Additionally, historical discrimination and mistreatment of African American patients in research have deterred their participation in research studies. This underscores the importance of cultural competence when recruiting and retaining African American patients in research studies (53). Given these challenges, conducting focus groups was not feasible, leading us to conduct six individual and group semi-structured interviews. Consequently, we did not have the benefit of interactive dialogue between participants typically fostered in a focus group setting, however, these interviews still provided valuable information and insight related to the intervention and its components. Data were collected in three distinct settings, with the goal of including African American patients and caregivers with differing socioeconomic backgrounds and lived experiences. This included an urban setting in Baltimore, Maryland, a rural setting in Salisbury, Maryland, and an urban area with surrounding suburban and rural communities in Birmingham, Alabama. While the findings of this study may not be generalizable to the broader African American population, this study offers valuable insights into the experiences and perspectives of African American patients across different settings. Despite the challenges with recruitment, the insights gained from this analysis have played a pivotal role in intervention

refinement and will be used to shape recruitment and enrollment strategies for the clinical trial.

Conclusions

In conclusion, this study provides evidence for the acceptability of a CHW palliative care intervention and its components for African American patients with advanced cancer and their caregivers. The findings of this study have led to intervention refinement, which will enhance implementation, delivery, and sustainability of the intervention.

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Footnote

Reporting Checklist: The authors have completed the COREQ reporting checklist. Available at <https://apm.amegroups.com/article/view/10.21037/apm-23-602/rc>

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the

Johns Hopkins Medicine Institutional Review Board (No. IRB00283002), which serves as a single-site IRB for this study, with reliance agreements in place with TidalHealth Peninsula Regional and University of Alabama at Birmingham. Informed consent was obtained from all individual participants.

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Table S1 Sample codebook including select codes and code definitions by content area

Code	Definition
Palliative care	
How they define palliative care	This code is used when participants provide their own understanding or interpretation of what palliative care means
Attitudes towards palliative care	This code pertains to the attitudes individuals hold about palliative care. This could encompass positive, negative, or neutral attitudes
Experiences with palliative and hospice care	This code applies when participants share their firsthand encounters or interactions with palliative care or hospice services
Patient navigation	
How they define patient navigation	This code is used when participants offer their own interpretations or descriptions of what patient navigation entails
Perceptions of patient navigation	This code pertains to participants' perceptions of patient navigation services
Experiences with patient navigation	This code applies when participants share their personal encounters or interactions with patient navigation services
CHW palliative care intervention	
Attitudes about the intervention	This code is used to capture participants' attitudes towards the CHW palliative care intervention
Perceived benefits of the intervention	This code pertains to participants' perceived benefits or advantages of the intervention
Implementation recommendations	This code applies when participants offer suggestions or recommendations related to the implementation of the intervention
Intervention delivery recommendations	This code pertains to participants' suggestions or recommendations related to how the intervention should be delivered
CHW recommendations	This code is used when participants provide recommendations related to CHWs involved in the intervention

CHW, community health worker.