Cancer in Women of the African Diaspora - Original Research Article

Cancer Control
Volume 30: 1–13
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DOI: 10.1177/10732748231162479
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Advance Care Planning With Black Women with Breast Cancer: A Community Health Worker Model

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Abstract

Background: Despite the importance of advance care planning (ACP), a process that optimizes future medical treatment and end-of-life care, for at-risk populations, rates of patient-provider ACP conversations are extremely low among Black women with breast cancer. Community health workers (CHWs) are well-positioned to support patients in engaging in ACP conversations with their providers; yet research on integrating CHWs to promote ACP is scant. The current study examined multilevel facilitators and barriers to successful ACP conversations among Black women from the perspective of providers and CHWs who serve this community.

Methods: Providers and CHWs were recruited from an academic medical center in a large urban city. Retrospective qualitative data on barriers and facilitators to ACP conversations, as well as CHWs' training needs, were collected from two focus groups (N = 5 providers, N = 5 CHWs) and one individual interview (N = 1 provider), and transcribed and coded for themes.

Results: All providers reported working primarily with Black patients, and identified stigma and time constraints as major barriers to ACP discussions; they also identified the structural barriers and injustices that their patients face during medical care. CHWs reported having a trusted relationship with their patients and flexibility in their care that would allow for ongoing ACP conversations, discussing their ability to serve as a bridge between the patient and provider. However, CHWs discussed that they lacked the tools and skills to have ACP conversations, largely because existing formal trainings in ACP are cost prohibitive.

Discussion: Competing priorities of the provider to discuss/treat the patient's disease and medical mistrust were major barriers to successful ACP conversations among Black women with breast cancer, leading to ACP completion occurring late in treatment. CHWs are uniquely qualified to overcome multilevel barriers to ACP and establish trusting relationships with patients in order to facilitate earlier and ongoing communication between patients and providers.

Keywords
palliative care, community health workers, advance care planning, health disparities, women, breast cancer

Received September 30, 2022. Received revised January 10, 2023. Accepted for publication February 7, 2023.

Introduction

Advance care planning (ACP) is an ongoing process of communication and shared decision-making in which patients establish goals and preferences for future care and codify these decisions in written documents, such as a living will, health care power of attorney, Medical Orders for Life-Sustaining Treatment (MOLST)/Physician Orders for Life-Sustaining

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Treatment (POLST) form, and do not resuscitate (DNR)/do not intubate (DNI) orders.[1–3] ACP is crucial to ensuring that patients receive care that is concordant with their values and wishes and allows them to make choices about their care now in the event that they become incapacitated and are unable to make medical decisions in the future.[2,3] Among patients with cancer, ACP is associated with benefits such as improved quality of life, reductions in unnecessary hospitalizations and futile, aggressive cancer treatments at end of life, and increased use of palliative care and hospice.[4,5]

Although breast cancer mortality rates have declined significantly in recent decades, Black women in the United States die from breast cancer at disproportionate rates compared to white women, despite having a lower incidence.[6] Black women with breast cancer are more likely to be diagnosed with more aggressive subtypes of breast cancer, such as triple-negative breast cancer, and are more likely to be diagnosed at more advanced stages of breast cancer.[1] Black women also commonly experience socioeconomic and social barriers to high-quality health care, including limited or no health insurance coverage, as well as perceived and structural discrimination.[7] Despite the importance of ACP for at-risk populations, rates of patient-provider ACP conversations are lower among Black patients with advanced cancer than white cancer patients.[1] As a result, Black patients with advanced cancer are less likely to receive care that is concordant with their preferences and are more likely to receive aggressive end of life care and forgo hospice.[8]

Individual- and systems-level factors contribute to racial disparities in ACP uptake (Figure 1). These individual factors (eg, a patient's understanding of their illness and ACP, spiritual and religious beliefs, and treatment preferences) intersect with mistrust of the healthcare system due to historic injustices and structural racism, as well as with the need for more training and standardization in ACP among oncology providers.[9] A Community Health Worker (CHW) is a frontline public health worker who is a trusted member of the community in which they serve.[10] This trusting relationship enables CHWs to serve as liaisons between health care services and the community in order to facilitate access and improve the quality of the services provided. The CHW care model is designed to address the social and structural barriers to care by providing services like psychosocial support, care coordination, and health education.[11] Recent evidence demonstrates that CHWs can increase engagement in ACP and improve symptom management, ultimately reducing hospitalizations and emergency room visits and increasing utilization of palliative care and hospice.[12] However, much more research is needed to understand the potential role of CHWs in ACP among diverse and vulnerable populations like Black women with breast cancer.[12] Therefore, the aim of the current study was to examine multilevel facilitators and barriers to successful ACP conversations among Black women with breast cancer from the perspective of providers and CHWs who serve this community. We also aimed to identify strategies needed to effectively integrate CHWs in promoting ACP in order to ensure that Black women with breast cancer receive care that is concordant with their preferences and goals across the cancer treatment continuum.

Methods

The reporting of this retrospective, qualitative study conforms to COREQ guidelines.[13]

Participants

The study team recruited participants at a major academic medical center in a large urban city via convenience sampling.

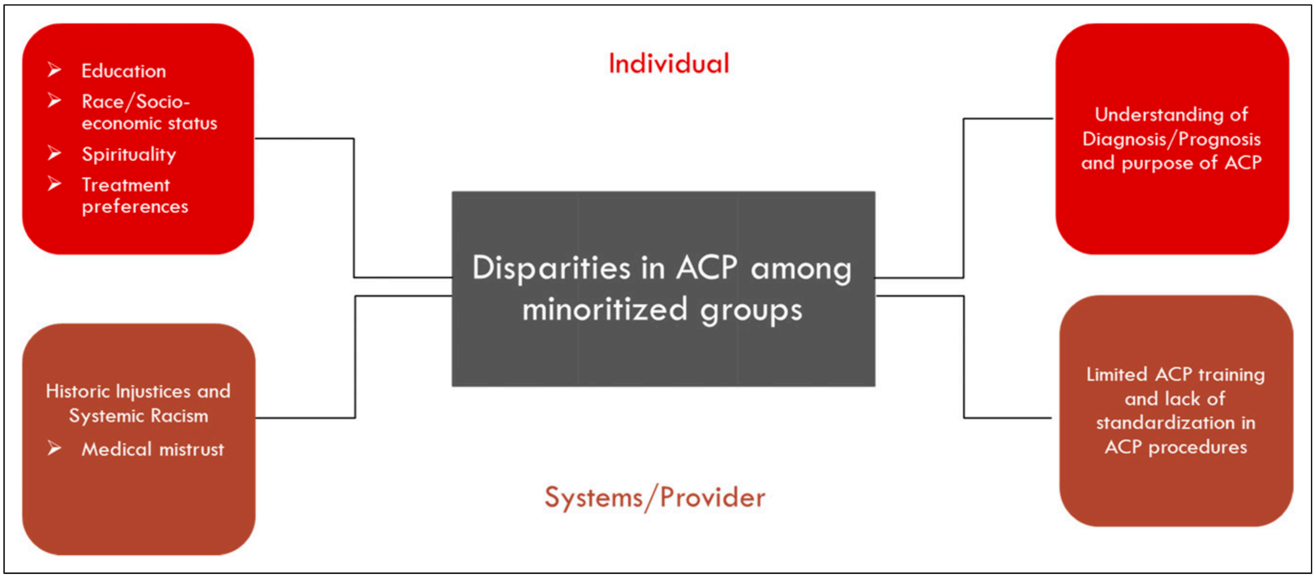


Figure 1. Disparities in advance care planning (ACP) experienced by minoritized groups.

Physicians and advanced practice providers (ie, physician assistants, nurse practitioner), who specialized in oncology or palliative medicine, and CHWs, who provided direct service to patients, were recruited for the study. The research team contacted 21 potential participants via direct email, which included an introduction to the P.I., the study, and invitation to participate. The final sample consisted of 6 providers and 5 CHWs.

Procedure

Two 60-minute semi-structured focus groups and one interview (N = 6 providers, N = 5 CHWs) were conducted virtually via Zoom during the summer of 2021; the individual interview was completed with one provider (n = 1) who had scheduling conflicts with the focus group session. After providing verbal informed consent, each participant completed a de-identified, pre-interview questionnaire (investigator-initiated) and provided information on demographics, the patient population they served, and previous ACP training or exposure. The focus groups and interview were co-led by two licensed clinical psychologists (PM and MT) and conducted using a focus group guide (see Supplementary Table) to facilitate discussion. Providers discussed their previous experiences, current practices, and attitudes regarding ACP, including challenges to having ACP conversations with their patients who are Black women, as well as factors that lead to good ACP conversations. They also discussed thoughts about integrating CHWs into ACP discussions with cancer patients. CHWs similarly discussed their experience and exposure to ACP and barriers and facilitators to ACP conversations with their patients, as well as their training needs regarding ACP with cancer patients. Participants received a gift card for completing the pre-interview questionnaires and participating in the focus groups. The study was approved as an Exempt study by the Institutional Review Board (approval # IRB21-0160).

Data Analysis

The focus groups and interview were audio recorded and transcribed by a member of the research team. Researchers also took notes during the interview process. Participants did not review the transcripts nor provide feedback on the findings. Qualitative data analysis was conducted using The Framework Method.[14] Two independent coders (one master's level and one doctoral level) created a preliminary codebook after an initial review of the transcripts. Next, the two coders worked collaboratively to finalize the codebook, and establish primary codes, secondary codes, and tertiary codes. Once the codebook and definitions were established, the coders used Dedoose software (version 9)[15] to independently code the transcripts. The coders used Dedoose's analyze feature, qualitative code application, to extract the main themes from the transcripts. In order to maintain consistency in coding, the coders met regularly to refine codes, merge codes, clarify code definitions, and independently re-coded multiple times. Codes that were frequently applied were extracted to identify the main themes from each focus group and interview.

Results

Sample characteristics can be found in Table 1. All six providers (n = 3 medical oncologists, n = 2 palliative medicine physicians, n = 1 radiation oncologist) reported spending the majority of their time in direct clinical care and working primarily with Black/African American patients; for a majority of providers (n = 4), >75% of their patients had been diagnosed with breast cancer. When asked about breast cancer patients in particular, providers self-reported that of their total patient panels, "*about 10-20%*" to "*50-60%*" were Black/African American women with breast cancer, depending on practice location and setting (ie, academic vs community practice). All providers had previous training in ACP, and a majority reported receiving previous training in ACP through continuous education units/continuing medical education.

All CHWs (N = 5) reported providing health education/information in their current position, and most reported providing healthcare access navigation services. Some CHWs reported receiving training in cancer prevention or screening, but only one had experience with active cancer treatment, and none with palliative care; about half had previous experience with ACP. All reported serving Black/African American patients, although only two worked with cancer patients.

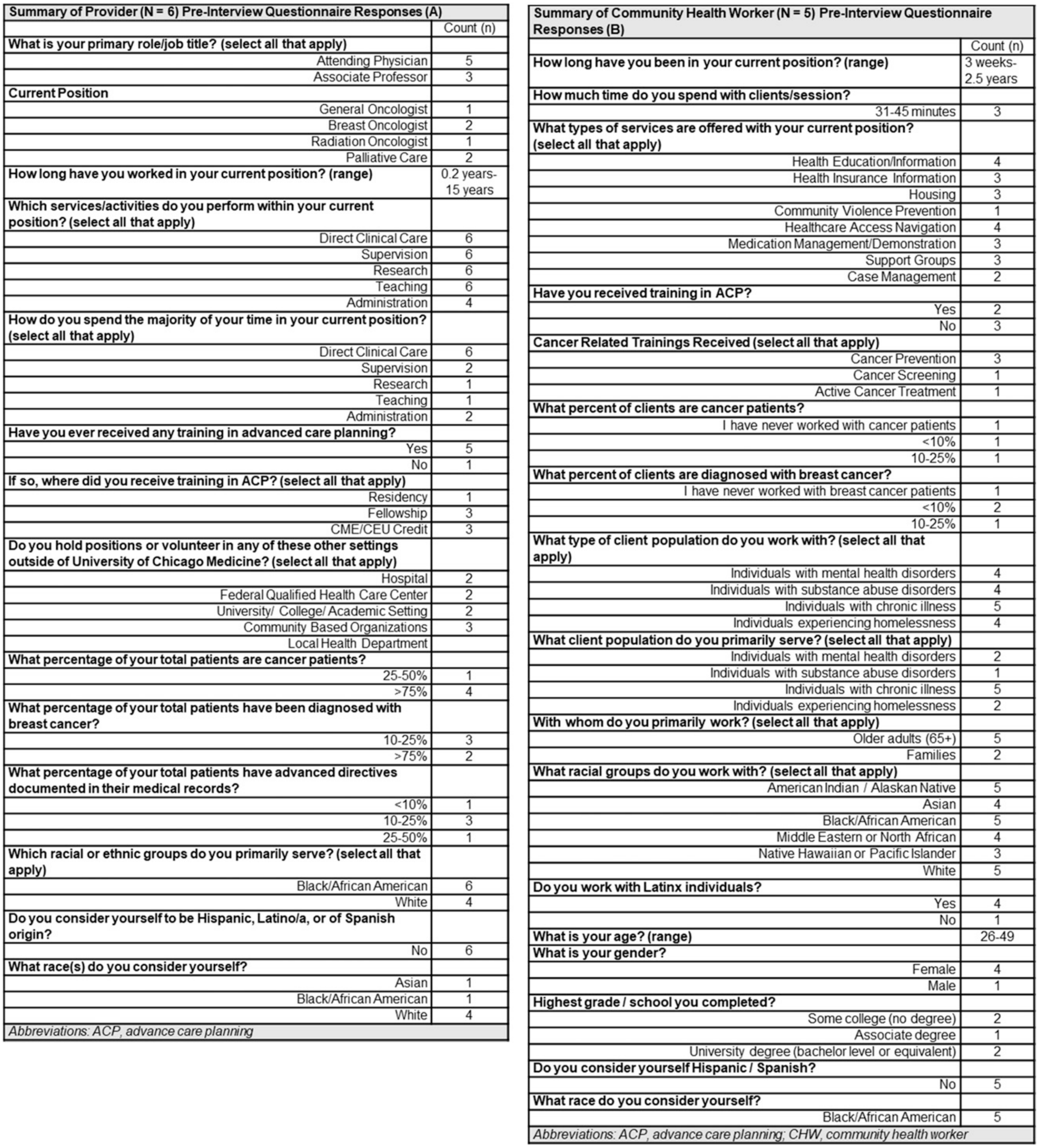
Barriers to ACP with Black Women with Breast Cancer

A total of 13 broad codes were created and applied to 500 excerpts (250 unique excerpts per coder) across three transcripts. Five broad themes and 18 sub-themes emerged. Illustrative quotes are in Table 2.

Provider barriers to initiating ACP

Two main themes arose when providers identified their own needs and barriers to ACP conversations: time constraints and stigma. Providers identified time constraints as a major barrier to initiation and maintaining ACP conversations, a barrier exacerbated by competing priorities on the part of the provider and patient. With limited time during appointments, "*it's difficult for me personally to introduce the idea early just cause there's so many other things going on...I do want to try to keep the focus on what options they have*" (Provider 2, breast medical oncology). Rather than talking about what will happen if treatment fails, the provider wants to focus on the possible treatment options. Timing of ACP conversations is also dependent on the patient's disease course and "*their trajectory to disease prognosis*" (Provider 4, breast medical oncology). If a provider has a patient that "*would have, potentially many, many years to live*"

Table 1. Sample Characteristics of Providers (A) and Community Health Workers (B).



Summary of Provider (N = 6) Pre-Interview Questionnaire Responses (A)	
	Count (n)
What is your primary role/job title? (select all that apply)	
Attending Physician	5
Associate Professor	3
Current Position	
General Oncologist	1
Breast Oncologist	2
Radiation Oncologist	1
Palliative Care	2
How long have you worked in your current position? (range)	0.2 years-15 years
Which services/activities do you perform within your current position? (select all that apply)	
Direct Clinical Care	6
Supervision	6
Research	6
Teaching	6
Administration	4
How do you spend the majority of your time in your current position? (select all that apply)	
Direct Clinical Care	6
Supervision	2
Research	1
Teaching	1
Administration	2
Have you ever received any training in advanced care planning?	
Yes	5
No	1
If so, where did you receive training in ACP? (select all that apply)	
Residency	1
Fellowship	3
CME/CEU Credit	3
Do you hold positions or volunteer in any of these other settings outside of University of Chicago Medicine? (select all that apply)	
Hospital	2
Federal Qualified Health Care Center	2
University/ College/ Academic Setting	2
Community Based Organizations	3
Local Health Department	
What percentage of your total patients are cancer patients?	
25-50%	1
>75%	4
What percentage of your total patients have been diagnosed with breast cancer?	
10-25%	3
>75%	2
What percentage of your total patients have advanced directives documented in their medical records?	
<10%	1
10-25%	3
25-50%	1
Which racial or ethnic groups do you primarily serve? (select all that apply)	
Black/African American	6
White	4
Do you consider yourself to be Hispanic, Latino/a, or of Spanish origin?	
No	6
What race(s) do you consider yourself?	
Asian	1
Black/African American	1
White	4
Abbreviations: ACP, advance care planning	

Summary of Community Health Worker (N = 5) Pre-Interview Questionnaire Responses (B)	
	Count (n)
How long have you been in your current position? (range)	3 weeks-2.5 years
How much time do you spend with clients/session?	
31-45 minutes	3
What types of services are offered with your current position? (select all that apply)	
Health Education/Information	4
Health Insurance Information	3
Housing	3
Community Violence Prevention	1
Healthcare Access Navigation	4
Medication Management/Demonstration	3
Support Groups	3
Case Management	2
Have you received training in ACP?	
Yes	2
No	3
Cancer Related Trainings Received (select all that apply)	
Cancer Prevention	3
Cancer Screening	1
Active Cancer Treatment	1
What percent of clients are cancer patients?	
I have never worked with cancer patients	1
<10%	1
10-25%	1
What percent of clients are diagnosed with breast cancer?	
I have never worked with breast cancer patients	1
<10%	2
10-25%	1
What type of client population do you work with? (select all that apply)	
Individuals with mental health disorders	4
Individuals with substance abuse disorders	4
Individuals with chronic illness	5
Individuals experiencing homelessness	4
What client population do you primarily serve? (select all that apply)	
Individuals with mental health disorders	2
Individuals with substance abuse disorders	1
Individuals with chronic illness	5
Individuals experiencing homelessness	2
With whom do you primarily work? (select all that apply)	
Older adults (65+)	5
Families	2
What racial groups do you work with? (select all that apply)	
American Indian / Alaskan Native	5
Asian	4
Black/African American	5
Middle Eastern or North African	4
Native Hawaiian or Pacific Islander	3
White	5
Do you work with Latinx individuals?	
Yes	4
No	1
What is your age? (range)	26-49
What is your gender?	
Female	4
Male	1
Highest grade / school you completed?	
Some college (no degree)	2
Associate degree	1
University degree (bachelor level or equivalent)	2
Do you consider yourself Hispanic / Spanish?	
No	5
What race do you consider yourself?	
Black/African American	5
Abbreviations: ACP, advance care planning; CHW, community health worker	

then they "*won't really address it [ACP] maybe until [the provider] start[s] their [the patient's] second line therapy*" (Provider 4, breast medical oncology). One provider attributed this reluctance to talk about end-of-life care to stigma that a patient dying means "*a failure on the part of the physician*" (Provider 6, radiation oncology). A provider noted that they may wait until "*they've exhausted all options*" (Provider 6, radiation oncology) before discussing ACP due to this fear of failure, instead of at an earlier time when there may be less pressure to make any decisions.

Table 2. Illustrative Quotes from Provider and Community Health Worker Focus Groups.

BROAD THEME[a]	SUB-CATEGORY	FOCUS GROUP	QUOTE
TIMING OF ACP DISCUSSION	**Competing priorities**	Provider 2	*"Um, and so, it's- it's definitely a balance where I definitely want to catch them before they get too sick, but I also think* ***it's difficult for me personally to introduce the idea early just cause there's so many other things going on****. And I-* ***I do want to try to keep the focus on what options they have****, um if that's- if that's the case, so."*
	Disease course	Provider 4	*"Um, and then I think kind of the broaching of um kind of advanced directives really depends on um for metastatic patients on their um,* ***their trajectory to disease prognosis****."*
	Disease course	Provider 4	*"This is like a first line after ER + positive breast cancer patient that* ***would have, potentially many, many years to live****. I-* ***I won't really address it maybe until I start their second line therapy****."*
	Earlier timing	Provider 6	*"I think the medical oncologists do a good job of it. It's just the, it's all about the timing, right? So,* ***generally, the timing is when they've exhausted all options****...And maybe that timing should be moved up."*
	Earlier timing	Provider 3	*"So, really collecting that goals and values information up front, and then um being able to use that information along the way. When a decision needs to be made, you can reference back to that and say, you know in our previous conversations you told me 'x' is very important to you, and um I'm concerned this may be at risk now um with the decisions we're making."*
	Earlier timing	CHW A	*"...we come from the community um we deal with some of the same issues and we* ***can probably have those conversations*** *as* ***before we need to have those conversations****, before the positions and things happen* ***before you just have to make decisions*** *and I think community health workers are an intricate part to the introduction of having those conversations without the fear in it for patients."*
PROVIDERS THOUGHTSTOWARDS ACP CONVERSATIONS	**Stigma around ACP**	Provider 6	*"I think medical school has done a horrible job of training physicians to be comfortable with discussing end of life care because they...****it's considered a failure on the part of the physician****."*
	Varying perspectives	Provider 6	*"One thing I would stress to them is we all look through our own cultural lens. And sometimes you need to step back and be aware of that because when you're approaching something it may be completely different than the way the person you're talking to is approaching things."*

(continued)

Table 2. (continued)

BROAD THEME[a]	SUB-CATEGORY	FOCUS GROUP	QUOTE
CONSIDERATIONS IN AFRICAN AMERICAN WOMEN	**Competing priorities**	Provider 2	*"Because obviously, if, you know,* ***they're still working or still the care giver for their family, it's much harder for them to, you know, even think sometimes about advanced care planning or have these conversations****. Or um, you know, work on these things just cause* ***there's a lot of other priorities in their life****."*
	Structural barriers	Provider 2	*"I definitely had a couple patients when I, you know, talk about, you know, what- what-what do you think about if things weren't going as well. We'll bring up the fact that, you know, their son is living with them and that they are the, you know, the-* ***they need to keep working or they need to keep being active in order to support the lifestyle of their whole family****."*
	Historic injustice	Provider 1	*"Um,* ***what support network do they have as far as helping them to get through this diagnosis and get through the management of care for the diagnosis? Um, what experiences have they had with other family members that have been through breast cancer?*** *Um,* ***what are some of the historic um historic, you know, injustices that have occurred that they've known about and heard about? And does that bring worry and concern about the type of care that they're going to receive?"***
	Prior experiences	Provider 1	*"So, I think in particular when-* ***when anyone is treating someone of a particular group that has had social injustice, you have to overcome that barrier before you can get to the 'we have this disease process that we're dealing with and that we have to help and support you with****.' And I think if you're able to really and truly put in a little bit of the work and try to get through where are some of the barriers, then you're able to form the best of clinical relationships and really able to help and support the patient and family."*
	Competing priorities	Provider 5	*"And uh, I think it's very important and I don't think this is uh really race specific, but uh to really understand the family dynamics at play and uh the infrastructure of the family, uh who they lean on for support, and like uh* [Provider *2] was saying, you know, often* ***they're being leaned on for support****, so uh- so* ***they're perspective of what they need to accomplish is different than what might be normal."***

(continued)

Table 2. (continued)

BROAD THEME[a]	SUB-CATEGORY	FOCUS GROUP	QUOTE
ROLE OF CHW	**Establish trust**	CHW A	_“So and_ **_people feel comfortable in their community. They feel comfort able talkin’ to those that they’re most connected to_** _so maybe train people that can start the conversation and reach back and out say hey this patient this person was talking about that.”_
	Bridge[b] (doctor and patient)	CHW B	_“Like what I know from when I’ve around my patients, they, *chuckles* they always, I have a lot patients who will say and I’m sure (name of participant) and (name of participant) can really attest to this, but they will say you know I talk to you as a community health worker, I talk to you I speak to you, ah and not_ **_some of the things I don’t even share with my doctor or with the nurse_** _and_ **_they trust us because we are a_** _their_ **_trusted member, right of the community_** _and so its a lot of things that they tell us that even their family members have no, they don’t even know.”_
	Bridge (family and patient)	CHW A	_“Yeah, so_ **_those are really hard conversations to have even with your family. I think it’s easier outsider but not an intimidating outsider_** _cuz um I,_ **_I tried_** _*chuckles*_ **_that too with my children and they was like mama we don’t wanna talk about it_**_, we don’t wanna talk about that.”_
	Flexible	CHW A	_“Um again, like (name of participant) said doing the zoom visits,_ **_we get a chance to see some of the things that we would typically see if we were going into the home_**_._ **_So seeing some of the clutter_**_ness,_ **_or seeing_** _some of the uh, um,_ **_what they don’t have, or what they need_**_, so um it’s much easier if we were actually in the homes to see it, but it is a new way.”_
	Establish trust	CHW A	_“I think that we come from the community, understand the community, have been there and_ **_he felt comfortable enough with me that I wasn’t in a white coat, I wasn’t in hospital, I was in his own personal setting in his home and he was able to have someone to help facilitate the conversation_** _with him.”_
	Non-threatening	CHW A	_“_**_I certainly believe that um community health workers should be in the realm of oncology because its a whole different beast and people are afraid and we are the non-threatening_** _you know supporting...we can be eyes and ears and we can also educate about what’s going on and reinforce education...”_
	Bridge	CHW A	_“What can we give the physicians to care for these patients,_ **_what what kind of insight can we give you from going into the home or receiving information from them that they won’t share with you all because they’re afraid_** _or whatever.”_
	Bridge	CHW A	_“We’re, we’re only here to be um, I, I like to say a extra sauce for the physicians. You know a secret, a secret sauce for the physicians you know so just giving you all_ **_the eyes and ears_** _and you know what you don’t see and like (name of participant) said, we share with you what patients um especially if it’s gonna affect their health or whatever.”_

(continued)

Table 2. (continued)

BROAD THEME[a]	SUB-CATEGORY	FOCUS GROUP	QUOTE
CHW BARRIERS TO ACP CONVERSATIONS	**Lack of formal training**	CHW A	*"**This is something very brand new**, so actually showing them what the health power of attorney looks like, who needs to [complete it] ...I'm excited to work with you all **to create something for community health workers because we come from the community** um **we deal with some of the same issues** and we **can probably have those conversations** as **before we need to have those conversations**, before the positions and things happen **before you just have to make decisions** and I think community health workers are an intricate part to the introduction of having those conversations without the fear in it for patients."*
	Lack of formal training	CHW A	*"**The training that I received was simply what I'm already giving my community health workers** is **the exposure to what that form looks like**, being in tune with what the patient is telling you, listening to what they're saying about dying and the fear and finding a way to interject the conversation. **So my training wasn't**, it wasn't um, **like a standard training** *chuckles*. It was just an exposure, I would say."*
	Expensive training	CHW B	*"I can't find anything that's offer you know for low to no cost"*
	Expensive training	CHW A	*"**Sometimes the agencies that they (CHWs) work for will not pay for trainings for them… and sometimes community health workers cannot afford the trainings**. And it's coming out of their own pocket…"*
	Pandemic factors	CHW B	*"It's been quite difficult because since we've been in the pandemic, conducting the home visits, of course...ceased. Um however, we are conducting clinical visits and um we do try to service our patients um through facetime, zoom, whatever we can. Um, but of course a lot of our patients um are not equipped um unfortunately with that so we have to do the telephonic calls."*
	Patient reluctance	CHW A	*"I think it is a very touchy subject for patients and it's a scary subject and then it's a taboo. You know, if you talk about it, it's gonna happen."*
	Responsibility	CHW A	*"**That's what the university is trying to do right now is trying to find out who should be having those conversations**. Um **should it be clergy, should it be the doctors**…**right now there is nothing in place**, like who who's having it and who who gets to scan it in a chart…it's just conversations…"*
	Responsibility	CHW A	*"If the conversation has already been initiated by a doctor or therapist or whatever, how do we support that um the person that has already started the conversation? Or are, would we be stepping on toes, or if the conversation hasn't been started, who gets to start it? Who should start it?"*
	Communication skills	CHW A	*"So, maybe giving us, giving community health workers the tools to have those reassuring conversations with the patients."*

CHW= community health worker; ACP=advance care planning.

[a] Broad themes follow the questions of the semi-structured nature of the interviews. Sub-themes include the second and tertiary themes of how the responses were coded within those broad themes.

[b] Definition: CHW can act as a liaison between doctors, patients, and patient's family to help communicate goals, wishes, and knowledge about the diagnosis.

Structural barriers to ACP for patients

When providers were asked to identify the needs of their Black/African American patients, two main themes emerged: structural barriers related to patients' roles and responsibility in their family life and prior experiences and interactions with the health system and the role of historic injustice. Providers recognized the importance of a patient's culture and family obligations and the significant impact this plays into the decision to engage in conversations on ACP in a timely manner. These considerations are often at odds with the provider's goals when attempting to discuss ACP, noting "*we all look through our own cultural lens. And sometimes you need to step back and be aware of that because when you're approaching something it may be completely different than the way the person you're talking to is approaching things"* (Provider 6, radiation oncology). If the patient is *"still working or still the care giver for their family, it's much harder for them to, you know, even think sometimes about advanced care planning or have these conversations… there's a lot of other priorities in their life*" (Provider 2, breast medical oncology). Having these conversations, especially when seen as a sign that treatment may not be successful can be difficult when "*[the patient is] being leaned on for support*" (Provider 5, geriatric oncology) by their families. A patient may "*need to keep working or they need to keep being active in order to support the lifestyle of their whole family*" (Provider 2, breast medical oncology). This creates a misalignment of goals between the patient and provider, as a patient's *"perspective of what they need to accomplish is different than what might be normal*" (Provider 5, geriatric oncology).

Providers described that prior experiences and interactions with the healthcare system affect the way that Black women with breast cancer approach healthcare decisions, including ACP. These experiences range from personal and family experiences to stories from friends and other patients: "*…what experiences have they had with other family members that have been through breast cancer?*" (Provider 1, palliative medicine). One provider urged others to consider surrounding factors around a patient's diagnosis, asking *"… what support network do they have as far as helping them to get through this diagnosis and get through the management of care for the diagnosis? Um, what experiences have they had with other family members that have been through breast cancer?"* (Provider 1, palliative medicine). These are all factors that are often overlooked when considering the complex interplay between a patient's culture and their willingness to engage in difficult conversations, and the complexity is further amplified with Black women who have faced systemic racism and injustice. One provider brought this up by asking us to consider these larger systemic barriers saying, "*what are some of the historic...injustices that have occurred that they've known about and heard about ...does that bring worry and concern about the type of care that they're going to receive?"* (Provider 1, palliative medicine). Thus, providers note that "*when anyone is treating someone of a particular group that has had social injustice, you have to overcome that barrier before you can get to the 'we have this disease process that we're dealing with and that we have to help and support you with'" (Provider 1, palliative medicine). A provider may think it is an appropriate time to have an ACP conversation, yet the conversation will not be successful if these barriers are not addressed first.*

CHW barriers to ACP conversations

When CHWs were asked about barriers to ACP conversations, the primary themes that arose were lack of formal training and unclear responsibility within the healthcare team. CHWs discussed the major barrier of having a gap in ACP knowledge, as "*this [ACP] is something very brand new*" (CHW A, worked with older adults with chronic disease) in the CHW model of care. Although most CHWs in the study had no experience working in oncology or palliative medicine settings, a few reported that their patients, especially older adult patients, managing chronic conditions have brought up concerns around end of life care to CHWs. For CHWs who have had experience in discussing ACP with their patients, the training that they received was informal. One CHW reported "*the training that I received was simply what I'm already giving my community health workers...the exposure to what the [power of attorney] form looks like...so my training wasn't...like a standard training*" (CHW A). CHWs mentioned cost as prohibitive factor to ACP training: "*sometimes the agencies that [CHWs] work for will not pay for trainings for them...and sometimes community health workers cannot afford the trainings*" (CHW A).

Another barrier that was discussed was the lack of clarity of the role CHWs had in completing ACP with patients. CHWs were worried about "*stepping on toes*" (CHW A) if a medical provider or psychologist already started the conversation with their patients, and they were unsure about how to support ACP conversations that were initiated. CHWs discussed an overall lack of clarity in which member of the medical team should initiate ACP conversations, noting "*that's what the University is trying to do right now is trying to find out who should be having those conversations…should it be clergy, should it be doctors?..right now there is nothing in place*" (CHW A). CHWs also agreed that they should have some training in basic principles in oncology so that they can have a general understanding of cancer-related treatments/processes so they can better work together with the healthcare team to facilitate ACP with Black cancer patients. One CHW highlighted "*I certainly believe that um community health workers should be in the realm of oncology because it's a whole different beast, and people are afraid and we [CHW] are the non-threatening...*" (CHW A).

Integrating community health workers into facilitating advance care planning conversations

One major theme discussed was that CHWs have a unique, trusting relationship with patients. CHWs are often members of the community, which helps mediate the power dynamic that patients often face with medical providers. As one CHW noted, "*people feel comfortable in their community. They feel comfortable talkin' to those that they're most connected to*" (CHW A). One CHW reported that a patient once said, "'*some of the things I don't even share with my doctor or with the nurse*'", highlighting the reason for patients' openness being *"they trust us because we are a... Trusted member, right of the community*" (CHW B, worked with older adults with chronic disease). Patients may be hesitant to talk to providers due to discomfort and/or mistrust, but CHWs noted that this discomfort may also extend to their own family: "*a lot of things that [the patients] tell us that even their family members… don't even know*" (CHW B). ACP conversations can be broad but can also be heavy conversations that are difficult to have with loved ones. As one CHW spoke from personal experience: "*those are really hard conversations to have even with your family. I think it's easier [to have with an] outsider but not an intimidating outsider... I tried... That too with my children and they was like mama we don't wanna talk about it*" (CHW A). CHWs see themselves as the safe, unbiased, third-party bridge for their patients to share their wishes and goals of care across various medical settings.

Another benefit of including CHWs in ACP conversations is that CHWs are flexible and are able to meet patients where they are, including in the patient's home or, as during the pandemic, virtually. One CHW said, "*we get a chance to see some of the things that we would typically see if we were going into the home. So, seeing some of the clutter..., or seeing...what they don't have, or what they need*" (CHW A). Having these conversations in a safe place, such as at home, can mean that "*[the patient feels] comfortable enough with me that I wasn't in a white coat, I wasn't in hospital, I was in his own personal setting in his home and he was able to have someone to help facilitate the conversation*" (CHW A). CHWs can help foster a sense of safety and comfort for patients while having difficult conversations about ACP. In addition, CHWs can be the bridge for physicians, as patients may share things with CHWs that they do not feel comfortable sharing with a doctor. One CHW asked, "*what kind of insight can we give you [the physician] from going into the home or receiving information from them [the patient] that they won't share with you all because they're afraid*" (CHW A). In this sense, CHWs say they can be the "*eyes and ears*" (CHW A) for physicians because CHWs have the opportunity to see personal and intimate aspects of the patient's life. CHWs expressed a desire to have a role in ACP conversations with patients, demonstrating excitement "*to create something for community health workers because we come from the community … we deal with some of the same issues*" (CHW A). CHWs also discussed their potential role in early initiation of ACP conversations, noting that CHWs "*can probably have those conversations…before we need to have those conversations…before you just have to make decisions.*" Integrating CHWs into ACP conversations would allow greater depth to these long-term conversations and help foster trust between the patient and the healthcare system. CHWs have the potential to serve as a trusted, cultural bridge in facilitating ACP conversations, thereby aligning patient, family and provider goals with care.

Discussion

The current study elucidated multilevel facilitators and barriers to initiating ACP conversations with this population, and explored ways in which CHWs are uniquely qualified to have these conversations with patients in order to convey the benefits of ACP and facilitate early completion. Results of this study revealed that CHWs have the potential to improve ACP by establishing trust with the patient in order to bridge the goals of the provider and the patient.

Both providers and CHWs emphasized that medical mistrust is a major barrier to engaging in ACP conversations with Black women with breast cancer. Research demonstrates that few Black patients with advanced cancer are interested in discussing advanced directives with their oncologist,[5] and discomfort sharing information with providers is often worsened by previous negative healthcare experiences. A history of medical injustice and systemic racism exacerbate feelings of mistrust between Black patients and their medical providers,[16] and medical mistrust is a driving factor in low ACP utilization among Black individuals.[16] As a result, Black patients diagnosed with advanced cancer are also less likely to receive end of life care that is aligned with their wishes.[8] Given that trust and positive relationship with providers increase the likelihood of ACP conversations,[17] our findings suggest that the trusting relationships and rapport that CHWs have with Black women with breast cancer are critical.

CHWs are often members of the community they serve, so they have an inherent understanding of their patients' perspectives regarding the healthcare systems. CHWs are also able to flexibly provide services to their patients, for instance meeting them in the patients' own homes, to create a safe, comfortable space for their patients to share and discuss their care needs.

Another finding is that stigma related to ACP can affect timing of these conversations, causing them to occur later. Providers discussed that ACP is seen sometimes as an indicator that treatment failed, or that the provider was not successful in treating the patient. As a result, providers may wait to initiate conversations given the patient's prognosis or treatment trajectory. Results also showed that even when providers are ready to have ACP conversations, patients may

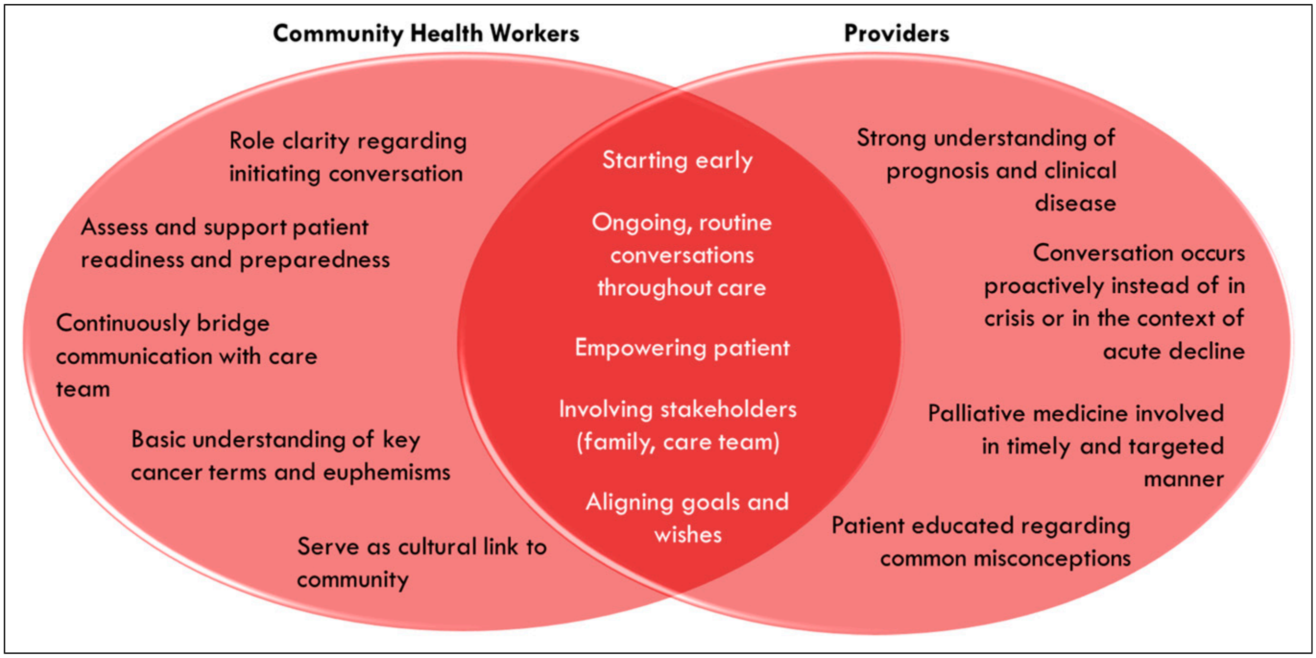


Figure 2. Components of a successful advance care planning (ACP) conversation: Synthesis of findings.

not be ready to prioritize ACP completion. In these instances, flexibility in care by CHWs, which can include more face-to-face time and longer follow up with patients, can be leveraged to increase readiness and preparedness to initiate ACP conversations. Furthermore, the fact that CHWs work to establish ongoing trust with patients and address their social determinants of health over time can support approaching ACP as a safe experience that continuously unfolds over time.

Emerging evidence shows that incorporating CHWs in cancer and palliative care has direct benefit on patient outcomes and use of support care services.[9,18,19] CHW-led interventions for ACP have demonstrated an increase in ACP among patients with advanced cancer, including higher rates of documentation of advanced directives and goals of care.[18] A pilot study with African American patients found that when CHWs encouraged ACP and use of palliative care, documentation of advanced directives increased from 24% – 75% over a one-year period.[9] Our findings suggest that several cross-cutting components may increase successful ACP conversations with Black women with breast cancer, such as starting the conversations early, engaging in the conversations in an ongoing and routine manner, empowering patients and involving important stakeholders, and clearly soliciting goals and wishes in order to align care with patients' priorities (Figure 2). Future programs and interventions should consider whether there is role clarity regarding who will initiate ACP conversations, CHWs' basic understanding of key cancer terms and euphemisms, and the CHWs' ability to assess and support patient readiness and preparedness, as well as continuously bridge communication with care team.

Limitations

Findings of the current study should be interpreted within the context of its limitations. Importantly, our data were collected as part of a larger project that aims to inform the development of a CHW-led intervention. The study utilized a small convenience sample of providers and CHWs employed by the same major academic medical center in a large urban city, which likely does not represent the experiences of providers and CHWs in other settings and limits the generalizability of our results. However, participants were recruited from a large, urban academic medical center that serves a large proportion of patients who are Black women (ie, 30% of patients with breast cancer). Focused research with more representative samples, including providers and CHWs employed in other geographic and healthcare settings such as community, rural, and federally-qualified healthcare settings, is urgently needed in order to ensure that diverse Black women with breast cancer are represented and supported in ACP.

Conclusion

ACP is critical to ensuring patients receive care that is concordant with their values and goals; however, trust and effective, culturally-sensitive communication are needed to initiate ACP conversations with patients, particularly among minoritized populations. Our findings suggest that CHWs are uniquely qualified to overcome multilevel barriers to ACP and establish trusting relationships with patients in order to educate patients on the benefits of ACP and facilitate ongoing communication between patients and providers.

Acknowledgments

We would like to thank the providers and community health workers that gave their valuable time to participate in this research.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Cancer Institute under grant number P20 CA233307 (MMT).

Research and Ethics Statement

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the University of Chicago's Institutional Review Board. This study was approved by University of Chicago Institutional Review Board (approval # IRB21-0160) as an exempt study. All individual participants gave verbal informed consent to participate in the study. This article does not contain any studies with animals or cell line research performed by any of the authors.

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Supplementary Material

Supplemental Material for this article is available on the online.

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