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The role of community health workers in a collaborative care management intervention for cancer pain management: a feasibility study for a randomized controlled trial

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Background: Despite the plausible role for community health workers (CHWs) in supporting historically disenfranchised patients experiencing cancer-related pain, few survivorship care models currently include CHWs. The purpose of our study was to learn from existing CHWs regarding the feasibility of working with rural dwelling and/or Hispanic/Latino patients and their cancer care teams; as well as assessing their anticipated barriers and facilitators of delivering a proposed collaborative care pain intervention [Achieving Equity through SocioCulturally-informed, Digitally-Enabled Cancer Pain manageme NT (ASCENT)].

Methods: Guided by the National Institute on Minority Health and Health Disparities (NIMHD) Research Framework, we recruited experienced CHWs to a mixed-methods feasibility study, including survey, interview and/or focus group. The survey assessed CHWs' comfort level with proposed intervention-related tasks (e.g., working with patients diagnosed with cancer). Interviews and focus groups explored potential training needs, as well as perceived intervention implementation barriers and facilitators. We summarized results using descriptive statistics and a rapid qualitative analytic approach.

Results: In total, 12 CHWs participated. Data included surveys (n=12), interviews (n=8), and a focus group with 4 participants. Overall, participant-CHWs felt confident they could participate in healthcare teams and remotely engage rural-dwelling and/or Hispanic/Latino patients diagnosed with cancer. Implementation barriers and facilitators included: working remotely in an unfamiliar geographic area, resource availability, technology, implementation-specific challenges, and patient level factors (e.g., loss of motivation).

Conclusions: Participant-CHWs viewed serving on a multidisciplinary healthcare team to support Hispanic/Latino and rural-dwelling cancer patients experiencing pain as feasible but identified training and resourcing needs.

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Introduction

Background

Community health workers (CHWs) are frontline public health workers who are trusted members of the community they serve. CHWs often share demographic, language, or other characteristics with the populations they prioritize. This trust and shared identity enables CHWs to be liaisons between healthcare or social service organizations and the community, thereby facilitating access to resources and enhancing the quality of services delivered (1). CHWs offer numerous services that may include interpretation and translation, culturally tailored health education, or guidance in accessing needed resources (2). Numerous studies have demonstrated that CHWs can successfully link patients to needed services that help mitigate social determinants of health (SDOH) (3-5), improve health outcomes (6-9) and enhance patient self-efficacy (10,11). CHWs can also be cost-effective and valued members of healthcare teams to address patient health needs (12,13).

Highlight box

Key findings
- Our findings suggest that community health workers (CHWs) can contribute in meaningful ways to supporting patients diagnosed with cancer as members of a collaborative care team to manage pain remotely. More research is needed to understand the impact of CHWs compared to collaborative care models alone.

What is known and what is new?
- CHW interventions are effective at improving outcomes such as cancer screening and health behaviors. To date, most research with CHWs has been in primary rather than speciality care (such as managing cancer symptoms). Hispanic/Latino and/or rural-dwelling patients have historically experienced disparities in cancer pain outcomes.
- To better serve this priority population, we are developing a trial to test a digitally-enabled collaborative care, team-based model that includes CHWs. Yet, little is known about the role of CHWs in collaborative care teams that support patients diagnosed with cancer. In this paper, we asked experienced CHWs about anticipated facilitators and barriers to implementing this model.

What is the implication, and what should change now?
- As CHWs become more integrated into speciality care teams, we encourage policy makers to expand CHW reimbursement models to include cancer survivorship.

Rationale and knowledge gap

Research suggests that underserved populations, including Hispanic/Latino and rural dwelling populations, face significant challenges in cancer survivorship (14,15). They struggle with limited access to oncology services and multi-disciplinary providers, clinical trial opportunities as well as travel barriers, persistent pain, and higher rates of cancer-related mortality (16,17). Despite (I) evidence to suggest that CHWs can be trained to support survivorship care for rural dwelling individuals (18); (II) the plausible role of CHWs in helping mitigate these known cancer survivorship disparities (19); and (III) the American Cancer Society's recommendation that healthcare institutions enhance service integration by collaborating with nonphysician community members to understand and address SDOH and advance cancer health equity (20), few trials have tested the impact of including CHWs in supporting patients with a cancer diagnosis (21) and none have looked at their role in supportive care for cancer-related symptoms.

Achieving Equity through SocioCulturally-informed, Digitally-Enabled Cancer Pain managemeNT (ASCENT) is a National Institutes of Health Helping to End Addiction Long-term Initiative (HEAL)-funded cancer care delivery trial being designed and implemented based on the concept of a digitally-enabled collaborative care, team-based model to treat patients that have historically experienced disparities in cancer pain outcomes, namely Hispanic/Latino and/or rural-dwelling patients. The proposed intervention aims to deliver stepped, patient-centered multi-modal pain care (MMPC) while concurrently addressing SDOH with the support of a CHW plus Nurse or Physical Therapist Pain Care Manager dyad, and regular clinical case management conferences (*Figure 1*). The intervention parameterized

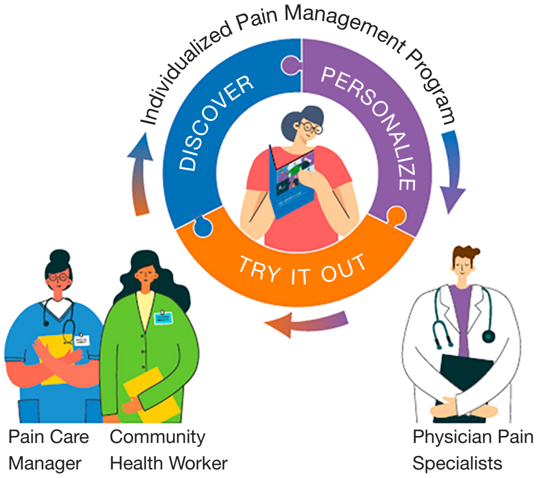


Figure 1 ASCENT collaborative care team. ASCENT, Achieving Equity through SocioCulturally-informed, Digitally-Enabled Cancer Pain managemeNT.

electronic health records (EHR) to systematically align care delivery with patients' sociocultural, linguistic, digital, and treatment preferences. Patients could opt to communicate via portal, text, email, video meetings, and/or phone calls. These choices were stored as discrete EHR data elements to automate and guide future outreach. The ASCENT intervention requires CHWs to become skilled at EHR-based communication.

Objective

We sought to learn about CHW's comfort with and how often they perform tasks necessary for ASCENT (e.g., navigating local resources remotely), training needs, and anticipated facilitators and barriers to implementing ASCENT. Our work was guided by Eldridge *et al.*'s pilot and feasibility studies conceptual framework. Because we asked experts (experienced CHWs) about intervention feasibility, our work falls within the 'feasibility studies that are not pilot studies' category (22). Additionally, we examined how anticipated ASCENT barriers and facilitators mapped to the National Institute on Minority Health and Health Disparities (NIMHD) Research Framework (23). This matrix includes domains and levels that influence health. In combination, the domains and levels create 20 cells that each reflect the scope of SDOH that may be relevant to pain disparities experienced by Hispanic/Latino and/or rural-dwelling patients and influence effective implementation. We used this model to organize our thinking around the scale and breadth of the potential factors the CHWs, research team, and healthcare institution would face in ASCENT. Our findings provide a blueprint for modifying the study design, developing intervention materials, and training CHWs to effectively address SDOH factors associated with cancer patient pain. Because a reporting checklist for non-randomized feasibility studies that are not pilot studies does not exist and this research was primarily qualitative, we present this article in accordance with the COREQ reporting checklist (24) (available at https://apm.amegroups.com/article/view/10.21037/apm-24-125/rc).

Methods

Because of the challenges inherent to adapting complex interventions such as ASCENT, pilot and feasibility work preceding a randomized control trial is recommended (25). Specifically, formative qualitative research can help plan for and mitigate trial uncertainties to better optimize interventions (26). Additionally, given the innovations to the CHW role in ASCENT (e.g., virtual format), it is critical to explore how best to integrate CHWs in a way that is feasible without losing the core elements that make CHW interventions effective (e.g., close relationships with patients). Thus, in this article we report mixed methods research using an explanatory sequential design (27) that explores how CHWs can best support rural-dwelling and/or Hispanic/Latino patients diagnosed with cancer who are experiencing pain. We asked experienced CHWs to characterize the feasibility of remote CHWs in supporting rural-dwelling and/or Hispanic/Latino patients with cancer pain management. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Mayo Clinic Institutional Review Board (No. 23-001838) and informed consent was obtained from all individual participants.

Participant recruitment

We used convenience and snowball sampling to recruit CHWs. The first author (A.M.L.) has collaborated with two of the CHWs on prior work since 2022. One of those participants recruited an additional participant and A.M.L. was introduced to the remaining nine participants through her professional network at the Mayo Clinic. We used this recruitment technique to quickly identify participants. We did not require CHWs to have a certification since this is not a requirement across all states.

To learn contextual details about working as a CHW, we recruited participants either currently employed by or contracted with the Mayo Clinic or working for organizations located in states where the Mayo Clinic or the Mayo Clinic Health Care System resides (Arizona, Florida, Iowa, Minnesota, and Wisconsin). We contacted participants via email. Twelve of the thirteen CHWs we approached agreed to participate in the study. The thirteenth CHW did not reply to our email.

Data collection

Using Research Electronic Data Capture (REDCap) (28,29), we first asked the CHWs to complete a brief questionnaire that included demographics and items written by the research team assessing participants' comfort in conducting the proposed ASCENT intervention activities and how often they typically performed those activities. The questionnaire included 33 quantitative and 3 qualitative questions and was available in English or Spanish (see Appendix 1). The first author (A.M.L.) then explained that she was an early career investigator conducting formative research to learn from experienced CHWs to enhance ASCENT intervention development. Finally, using narrative methodology to understand CHWs' experiences, A.M.L. conducted either an individual interview or focus group with participants in their preferred language (English or Spanish) via video conference or in-person. To make data collection more efficient, one CHW team participated in a focus group rather than individual interviews. The last author (J.D.A.) acted as notetaker during the focus group. The semi-structured interview/focus group guide (see Appendix 1) elicited information on prior and future training needs for CHWs, current workflows/responsibilities, and anticipated barriers and facilitators to supporting rural-dwelling and Hispanic/Latino patients diagnosed with cancer. We did not conduct any repeat interviews.

Although the National Cancer Institute's definition of 'cancer survivor' encompasses all patients alive with known or treated cancer (30), outside of academia 'cancer survivors' are often seen as people who have completed cancer treatment. Because we were unsure of the participant-CHWs' familiarity with cancer-related vocabulary, we used 'patients diagnosed with cancer' during data collection. Thus, we will use that terminology in this manuscript. Each interview lasted 30–40 minutes and the focus group was 75 minutes. We used Olympus digital voice recorders (DS-30) or video conferencing software to record audio data. All participants received renumeration. Data collection continued until we achieved data saturation (31).

Data analysis

We performed descriptive analysis of survey data. The interviews and the focus group were audio-recorded, transcribed, translated into English when applicable using a Health Insurance Portability and Accountability Act (HIPAA)-certified third-party vendor and analyzed by two team members (A.M.L., J.D.A.). We did not return transcripts to participants for comment or correction. Using Microsoft Excel, we analyzed the interview and focus group data using rapid qualitative analysis (32,33). Rather than producing deep theoretical insights, this pragmatic method identifies or enhances our understanding of key intervention elements, facilitators, and/or barriers in response to time-sensitive research implementation questions (34). We used the matrix method to systematically summarize the data and analyze by case and code (see Appendix 1). We maintained rigor and validity by independently assigning data in the matrix and discussing differences (35,36) and mapped the identified barriers to the NIMHD Research Framework. We shared a summary of our findings as well as a draft of this manuscript with participants via email and incorporated their feedback.

Research team reflexivity

AL learned Spanish in school and abroad. She identifies as a non-Hispanic White woman born in the United States (US), holds a PhD in health promotion and behavioral sciences, has extensive experience and training in qualitative research methodologies, and is currently research faculty at the Mayo Clinic. None of the authors are cancer survivors but all have experience collaborating with the rural-dwelling and/or Hispanic/Latino communities including work on past cancer research projects.

Results

Survey findings

We received 12 completed surveys from participant-CHWs in Minnesota and Florida (100% response rate). On average,

Table 1 Demographic characteristics of the ASCENT formative research study participant-CHWs

Characteristics†	Total (n=12)
Age (years)	44±10
Gender identity: woman	11 [92]
Location	
Florida	2 [17]
Minnesota	10 [83]
Born in the United States	5 [42]
Ethnicity	
Hispanic/Latino	8 [67]
Race	
Black or African American	2 [17]
White	10 [83]
Languages spoken‡	
English	11 [92]
Spanish	7 [58]
Other	2 [17]
Time working as a CHW (years)	7±7
Employer type‡	
Hospital or clinic	7 [58]
Non-profit organization	5 [42]
State or county health department	2 [17]
Other	1 [8]
Relationship to Mayo Clinic	
Employee or contractor	7 [58]
Not employed by Mayo Clinic	5 [42]
Time working at current organization (years)	6±7
Average percentage of work in person	78±32
Average percentage of work online	22±32
Completed or enrolled in a CHW certification	10 [83]

Data are presented as mean ± standard deviation or n [%]. †, the percent missing was 0%; ‡, participants could select more than one response thus the percentages do not sum to 100. ASCENT, Achieving Equity through SocioCulturally-informed, Digitally-Enabled Cancer Pain managemeNT; CHW, community health worker.

participant-CHWs were 44 years old [standard deviation (SD) =10], and 92% identified as female. Less than half were born in the US (42%) and the majority identified as Hispanic/Latino (67%). The average time working as a CHW was 7 years. Many participant-CHWs were employed by multiple organizations with 58% working for a hospital or clinic, 42% working for non-profit organizations, and 17% working for a state or county health department. Over half were employees or contractors with the Mayo Clinic (58%). The participant-CHWs conduct most of their work in person (78%) while about 22% of their time is dedicated to working with clients online (*Table 1*).

Feasibility of proposed CHW role

In ASCENT, we are asking CHWs to assess and address SDOH-related barriers to receipt of recommended pain care among rural-dwelling and/or Hispanic/Latino patients diagnosed with cancer. They are additionally asked to present SDOH issues during case management conferences with clinicians. To better understand participant-CHWs' current experience and the perceived feasibility of this role, we asked how often they work with the ASCENT priority populations and their comfort performing intervention tasks.

Most of the participant-CHWs (67%) work with Hispanic/Latino patients while less than half (42%) work with rural-dwelling patients daily. The frequency that they reported working with patients diagnosed with cancer was mixed: 8% each responded, 'every day' and 'never', 25% each stated 'once or twice a year' and 'once a week', and 33% answered 'once a month' (*Figure 2*).

All participant-CHWs reported that they were 'comfortable' or 'very comfortable' working with a healthcare team to help patients with cancer manage their pain. Most respondents (92%) stated they were comfortable working as CHWs with patients diagnosed with cancer and working with digital technologies like video conferencing software. Three-quarters of the participant-CHWs reported feeling comfortable working with patients remotely, working with EHRs, and working with patients online who live in an unfamiliar geographic area (*Figure 3*).

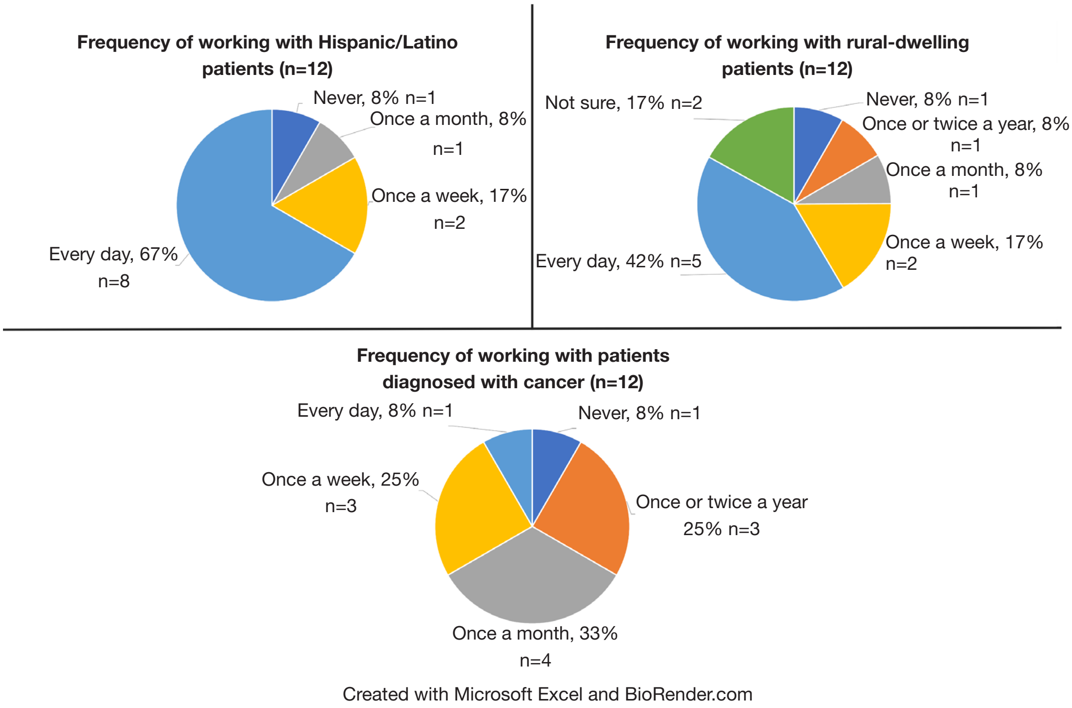


Figure 2 The frequency community health worker participants reported working with rural dwelling and Hispanic/Latino patients and patients diagnosed with cancer.

Anticipated barriers to ASCENT implementation

We conducted eight individual interviews and one focus group with four participants. The team categorized data into five groups that align with the NIMHD Research Framework. We listed the NIMHD Research Framework domain(s) and level(s) and SDOH in parentheses below.

Working remotely in an unfamiliar geographic area

Although our survey results showed that participant-CHWs were comfortable working with patients remotely or in unfamiliar geographic areas, during qualitative data collection they identified barriers. The participant-CHWs reported that it would be challenging to build trust when they were not familiar with the patient's location, local resources, or preferences (physical/built environment/community: community resources). They also acknowledged that not being physically present with patients would hinder their ability to develop personal relationships. The participant-CHWs stated that patients often want face-to-face interactions and appreciate when CHWs conduct home visits. In turn, home visits are a way for CHWs to learn about the patient's life (healthcare system/interpersonal: patient-CHW relationship).

Resource availability

The participant-CHWs highlighted challenges around helping patients with limited access to resources. They discussed that rural-dwelling individuals may experience challenges with transportation and/or have limited options for accessing resources (e.g., speciality care) (physical/built environment/community: community resources). The participant-CHWs also described challenges experienced by individuals without legal citizenship or residency status who do not qualify for many resources. Consequently, a cancer diagnosis can not only mean physical but also financial and psychological pain around decisions to return to their countries of origin. One participant-CHW even described her organization's lack of trust in specific rural providers due to an unwillingness to serve individuals without legal citizenship or residency status (sociocultural environment/societal: societal structural discrimination).

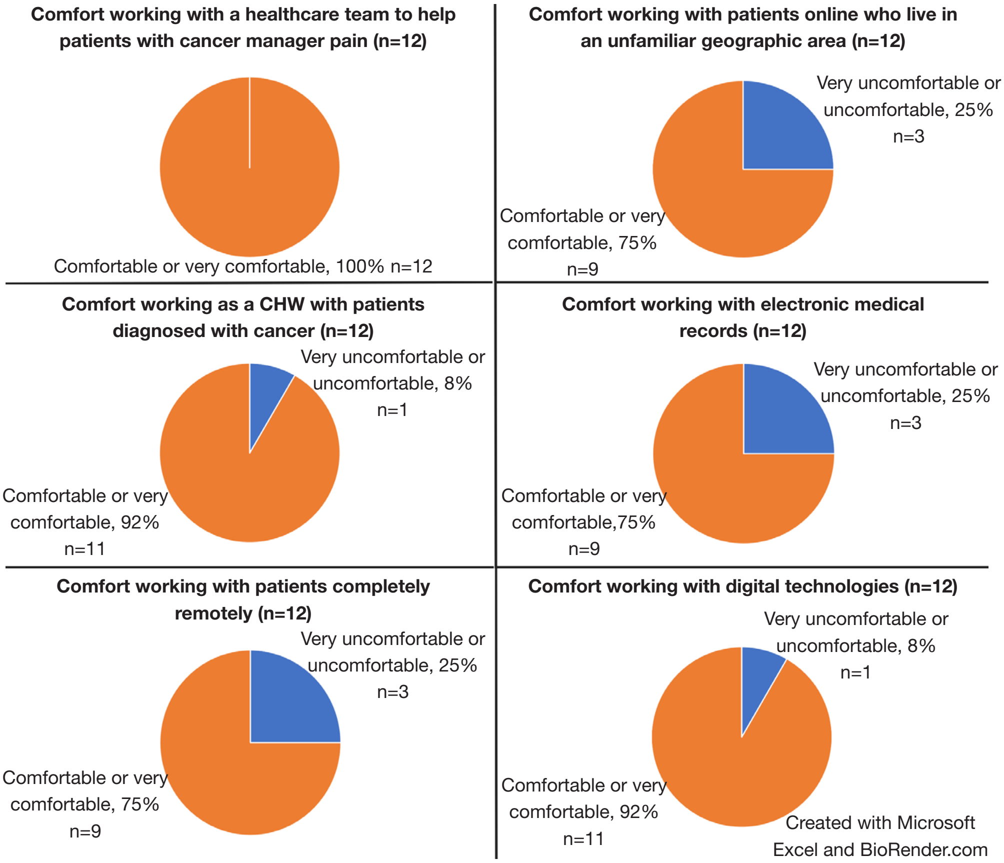


Figure 3 Community health worker participants' comfort performing tasks necessary for the ASCENT trial (n=12). CHW, community health worker; ASCENT, Achieving Equity through SocioCulturally-informed, Digitally-Enabled Cancer Pain managemeNT.

Technology

The participant-CHWs reported patients' lack of internet connection, computer, or cell phone as well as low digital literacy and hearing loss as potential barriers to CHWs' working remotely with Hispanic or rural-dwelling patients (physical/built environment/individual: personal environment; healthcare system/individual: health literacy; biological/individual: biological vulnerability and mechanisms). For speakers of languages other than English, the participant-CHWs also identified automated phone messages delivered in English as a barrier to accessing healthcare. They anticipated that it could be challenging to schedule appointments from a distance (by phone or video chat instead of in-person) (healthcare system/community: availability of health services).

Implementation-specific challenges

We asked participant-CHWs to reflect on potential barriers to implementing a collaborative care model to improve pain management. If the ASCENT CHWs do not share patients' cultural background and/or are not bilingual, participant-CHWs anticipated struggles to build trust (sociocultural environment/individual: cultural identity). We also asked participant-CHWs to reflect on situations that were outside CHWs' scope of practice. They described the following tasks as beyond their scope: completing specific forms (e.g., disability applications), answering medical questions (about diagnosis, medications, lab results, or nutrition), and transporting patients in their own vehicles. When asked how they managed these tasks, the participant-CHWs reported seeking help from their supervisor, a patient's care team, or other experts, as well as clarifying their role.

While most participant-CHWs work with healthcare professionals in teams, many described common misconceptions healthcare professionals and patients have about CHWs. While some healthcare professionals may think that CHWs are not valuable members of healthcare teams, both patients and healthcare professionals confuse the CHW role, thinking of them as language interpreters, social workers, or—in the case of patients—medical providers (healthcare system/individual: health literacy). The participant-CHWs were also concerned that the CHWs may hesitate to ask for help if they feel like a burden to the healthcare team (healthcare system/interpersonal: cross-disciplinary relationships). Additionally, the participant-CHWs were concerned about having insufficient time dedicated to each patient, especially if diagnosed with advanced cancer (healthcare system/societal: quality of care).

Patient-level factors

The participant-CHWs identified several patient-level factors that could hinder efforts to improve pain management for Hispanic and/or rural-dwelling patients diagnosed with cancer.

- Patients' experience with pain and co-occurring symptoms: participant-CHWs discussed how depression can cause patients to lose motivation for life, negative treatment side effects (e.g., lack of desire to eat) which may lead patients to stop taking medications, or disconnection from social life (biological/individual: biological vulnerability and mechanisms).
- Means of delivery: participant-CHWs worried that repetitive questionnaires would be bothersome for patients especially when they feel sick (behavioral/individual: health behaviors and coping strategies).
- Sociocultural factors: one CHW described the challenges of working with patients with racist beliefs which manifested as a desire to only work with CHWs of a certain race (sociocultural environment/interpersonal: interpersonal discrimination) (note: Mayo Clinic prohibits discrimination on the basis of race, color, creed, religion, gender, sexual orientation, gender identity or expression, national origin, age, disability or any other personal attribute from any patient or visitor). Another CHW brought up cultural stigmas surrounding people diagnosed with cancer—such as the idea that they will die imminently—and how these beliefs can negatively impact patients (sociocultural environment/societal: societal norms) (*Figure 4*).

Recommendations for including CHWs in collaborative care models with interdisciplinary care teams

To facilitate the inclusion of CHWs in collaborative care teams as in the ASCENT intervention, the participant-CHWs made the following recommendations.

CHW training needs

Team leadership should train CHWs on the geographic area served, how to effectively complete aid applications, disease specific information, basic first aid and comfort, data collection procedures, and mental health.

Recruitment and retention

Team leadership should ensure that language interpretation matches patients' country or region of origin and that patients always work with the same CHW and interpreter, include comfort communicating online in the patient eligibility criteria, and include home visits and/or provide transportation for CHWs or patients to visit.

Implementation (by role)

CHWs:

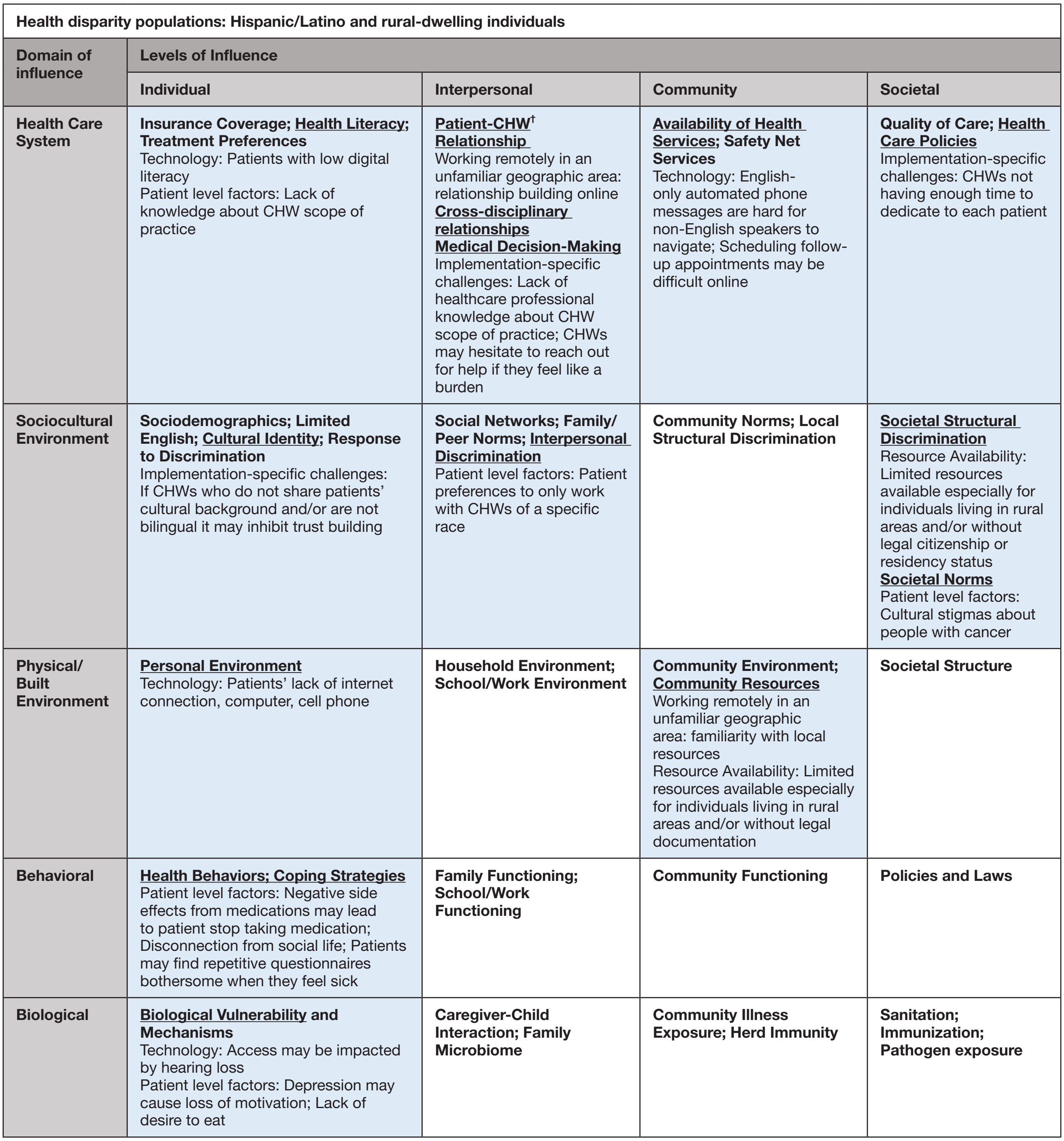
- Research local resources.
- Educate patients about the CHW role and scope of practice and basic cancer information.
- Ensure patients understand study and care plan.
- Be accessible, flexible, empathetic, and reliable.
- Listen and provide emotional support.
- Share new information gathered outside provider appointments with care team.
- Navigate cultural barriers and strive to integrate culture, family, and patient needs.

Team leadership:

- Hire CHWs who love their job and are dedicated to helping patients.
- Trust and empower CHWs to do their work.
- Educate providers about CHW scope of practice.
- Clearly delineate social worker, interpreter, and CHW roles.
- Establish bidirectional communication expectations and identify a point of contact who is available for CHW questions.
- Include CHWs in care consults.
- Ensure that CHWs have scheduling support or sufficient time set aside for follow-up.
- Avoid setting overly high expectations regarding CHWs' ability to find and help patients access resources.

Healthcare institution:

- Provide technological support for patients.
- Hire more providers from health disparity populations (*Table 2*).



Health disparity populations: Hispanic/Latino and rural-dwelling individuals				
Domain of influence	**Levels of Influence**			
	Individual	**Interpersonal**	**Community**	**Societal**
Health Care System	**Insurance Coverage; Health Literacy; Treatment Preferences** Technology: Patients with low digital literacy Patient level factors: Lack of knowledge about CHW scope of practice	**Patient-CHW[†] Relationship** Working remotely in an unfamiliar geographic area: relationship building online **Cross-disciplinary relationships** **Medical Decision-Making** Implementation-specific challenges: Lack of healthcare professional knowledge about CHW scope of practice; CHWs may hesitate to reach out for help if they feel like a burden	**Availability of Health Services; Safety Net Services** Technology: English-only automated phone messages are hard for non-English speakers to navigate; Scheduling follow-up appointments may be difficult online	**Quality of Care; Health Care Policies** Implementation-specific challenges: CHWs not having enough time to dedicate to each patient
Sociocultural Environment	**Sociodemographics; Limited English; Cultural Identity; Response to Discrimination** Implementation-specific challenges: If CHWs who do not share patients' cultural background and/or are not bilingual it may inhibit trust building	**Social Networks; Family/Peer Norms; Interpersonal Discrimination** Patient level factors: Patient preferences to only work with CHWs of a specific race	**Community Norms; Local Structural Discrimination**	**Societal Structural Discrimination** Resource Availability: Limited resources available especially for individuals living in rural areas and/or without legal citizenship or residency status **Societal Norms** Patient level factors: Cultural stigmas about people with cancer
Physical/ Built Environment	**Personal Environment** Technology: Patients' lack of internet connection, computer, cell phone	**Household Environment; School/Work Environment**	**Community Environment; Community Resources** Working remotely in an unfamiliar geographic area: familiarity with local resources Resource Availability: Limited resources available especially for individuals living in rural areas and/or without legal documentation	**Societal Structure**
Behavioral	**Health Behaviors; Coping Strategies** Patient level factors: Negative side effects from medications may lead to patient stop taking medication; Disconnection from social life; Patients may find repetitive questionnaires bothersome when they feel sick	**Family Functioning; School/Work Functioning**	**Community Functioning**	**Policies and Laws**
Biological	**Biological Vulnerability and Mechanisms** Technology: Access may be impacted by hearing loss Patient level factors: Depression may cause loss of motivation; Lack of desire to eat	**Caregiver-Child Interaction; Family Microbiome**	**Community Illness Exposure; Herd Immunity**	**Sanitation; Immunization; Pathogen exposure**

Figure 4 Mapping the barriers to implementing a collaborative care model to improve pain symptom management to an adapted version of the National Institute of Minority Health and Health Disparities Research Framework. [†], the NIMHD Research Framework includes example determinants within each cell (bolded text). These examples are not intended to be exhaustive, thus in two cases we adapted the examples to better fit our results (e.g., instead of 'patient-clinician relationship' we used 'patient-CHW relationship' and added 'cross-disciplinary relationships'). We underlined the determinants represented in our data. NIMHD, the National Institute on Minority Health and Health Disparities; CHW, community health worker.

Table 2 Barriers and facilitators to implementing a collaborative care management intervention for cancer pain management identified by experienced community health workers

Category	Relevant NIMHD Research Framework domain(s)/level(s) and health determinant	Barriers	Representative quote	Related facilitators by group (CHWs, research team, or healthcare institution)	Representative quote
Working remotely in an unfamiliar geographic area	Healthcare system/interpersonal: patient-CHW relationship[†] Physical/built environment/ community: community resources	- Relationship building online - Familiarity with local resources	"I know it's not the same. But I can see they are grateful for the call. When I make the call, sometimes they say 'I was waiting for your call'. Just 'I'm feeling fine, but I'm just waiting for your call just to talk'. That's something that at least we can do that, not being there in person. But all the time, they say, I wish we could see each other at least once."—Interviewee 6	CHWs: - Research local resources and environment (e.g., insurance coverage in rural areas) and connect with outside organizations or groups (e.g., community fundraising) around resources Mayo does not offer Research team: - Ensure patients always work with the same CHW and interpreter for consistency - Provide training about the geographic area served	"When I don't have the information, I look it up. That's what I mean that for me it's very important to learn and have a lot of resources because it's like having a box of tools."—Interviewee 5 "I think, especially with these patients: to have the same CHW. That way they know their history. They know them very well, not like they're gonna have to start all over and tell them their history."—Interviewee 7
Resource availability	Physical/built environment/ community: community resources Sociocultural environment/societal: societal structural discrimination	Limited resources available especially for individuals living in rural areas and/or without legal documentation	"Patients, when they're undocumented, the pain is more towards not be able to pay for what they need. I think that's some worst pain that they can have, than having this health problem with cancer. Unfortunately, we live in a world where, we want to help our patients but at the end of the day, it's the laws, that sometimes they stop everything and there's nothing that you and I or anybody can do about it. And that's the hardest thing."—Focus Group Participant 4	Research team: - Avoid setting expectations too high. Some people believe CHWs can solve all patients' problems but, CHWs are not magic and cannot connect people to non-existing resources - Teach CHWs how to effectively complete aid applications	"I can't help with housing. That's a United States problem. It's not a local problem: affordable housing. It's non-existent right now. And so, people want me to find somebody housing, because maybe they're getting evicted."—Interviewee 1 "I think we have really big hearts, and we really try to help people out. And it's hard when we can't find the resources, it's really hard."—Interviewee 3
Technology	Physical/built environment/ individual: personal environment Healthcare system/individual: health literacy healthcare system/community: availability of health services Biological/individual: biological vulnerability and mechanisms	Technology challenges: - Patients' lack of internet connection, computer, cell phone - Patients with low digital literacy - English-only automated phone messages are hard for non-English speakers to navigate - Scheduling follow-up appointments may be difficult online - Hearing loss	"Youth today go to school, and they're learning with the computer...We are old fashioned, and we're used to seeing somebody. If it's on the computer… they may see it as a problem."—Interviewee 5	Research team: - Include comfort communicating online in the ASCENT eligibility criteria - Include the option to meet patients in person through home visits and/or provide transportation for CHWs or patients to visit Healthcare institution: - Provide technological support to ensure that patients can access online services	"It's really hard, it's hard for far away, the relationship with the client. It's just, I think home visits are better especially how the mental health of the person is. I think we are humans and now we replace them for computers which is not the same thing."—Interviewee 8
Implementation-specific challenges	Sociocultural environment/ individual: cultural identity	If CHWs who do not share patients' cultural background and/or are not bilingual it may inhibit trust building	"I don't speak Spanish, so… I think for some patients that could be an issue because having that extra step of having an interpreter, stuff can get lost in translation."—Interviewee 3	CHWs: act as an interpreter or ensure interpretation matches patient's region or country of origin Research team: hire CHWs who love their job and are dedicated to helping patients Healthcare institution: hire more providers from the priority populations served	"For us, patient comes first. We wanna give those little things so our patients, so at the end of the day, they feel that we did something for them, and we did something for you, like back and forth. So, for us it's whatever it comes we'll take, because at the end of the day, we do it for our patients."—Focus Group Participant 4

Table 2 (*continued*)

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Category	Relevant NIMHD Research Framework domain(s)/level(s) and health determinant	Barriers	Representative quote	Related facilitators by group (CHWs, research team, or healthcare institution)	Representative quote
	Healthcare system/interpersonal: cross-disciplinary relationships†; medical decision-making	Lack of healthcare professional knowledge about CHW scope of practice	"They have to rely more on us [CHWs] and talk more to us as a bridge for the community and pay more attention so what we can see when we go to home visit, for example, or they go to see us at the clinic: have more communication between the clinician and ourselves. Because sometimes they skip us, they only focus on the patient. But they don't listen what we saw. Use more, use the community health workers as a good tool to understand more the patient and the family."—Interviewee 6	Research team: - Trust and empower CHWs to do their work - Educate providers about CHW scope of practice - Clearly delineate social worker, interpreter, and CHW roles - Establish bidirectional communication expectations and identify a point of contact who is responsive and available for CHW questions - Include ASCENT CHWs in care consults. Give them access to patient medical history including expectations, symptoms, pain management options, treatment, follow-up schedule, additional support needed apart from pain, and personal information - Train ASCENT CHWs about cancer (e.g., how to communicate with patients diagnosed with cancer and how pain medications work), basic first aid and comfort, and data collection procedures	"Make sure that we are [in] the position that we can provide education about the illness, about that, not the treatment itself, not about what kind of medications, but we can guide the patients for taking the medication every day, and make sure that if they have side effects they can talk to us, and the provider has to know that we can provide the services… If we don't know some certain things, they [the providers] feel comfortable that we are gonna ask them if we are doing the right thing."—Interviewee 6
		CHWs may hesitate to reach out for help if they feel like a burden	"I think that I have kind of an issue with not always asking for help when I probably should… I feel like a lot of times the team leads are giving us [CHWs] stuff that they don't have time for, and so I don't want to go back and say, hey: you know I really need help with this… I hate to bother them, I guess, with something that I can handle."—Interviewee 3		"I love to learn. I think that knowledge is like a treasure. The more you learn, the bigger your treasure is."—Interviewee 5
	Healthcare system/societal: health care policies	CHWs do not have enough time to dedicate to each patient	"But the challenge is: we can't be at the bedside all the time and need more time to schedule appointments to be with the patient regularly and that is hard, because we have other things to do."—Interviewee 6	Research team: - Ensure that the CHW has scheduling support or time set aside to follow-up with patients	"So you maybe we have to have a schedule, a specific schedule for each patient to follow up [with] them very continuously for them to feel our support."—Interviewee 6
Patient level factors	Biological/individual: biological vulnerability and mechanisms	Symptoms and study participation - Depression may cause loss of motivation - Negative side effects from medications may lead to patient stop taking medication - Lack of desire to eat - Disconnection from social life - Patients may find repetitive questionnaires bothersome when they feel sick	"Sometimes depression is severe, and makes them be negative, and makes them want to die now. They don't want to wait. It's torture to be alive. There are no more dreams. Why would they do something if they're going to die? That idea is very much alive in them, and it blocks them."—Interviewee 5	CHWs: - Ensure patient understands study and care plan: how to determine if an appointment is needed, who to go to with questions, anticipated outcomes, timeline, and options - Be accessible, flexible, empathetic, and reliable - Listen and provide emotional support - Share new information gathered outside provider appointments with care team	"My patient that has breast cancer… when I did my first initial appointment with her, she was depressed like she wanted to give up… And I remember going into the clinic and I talked to my supervisor and the nurse and then we contact her social worker. And I asked them: how far can I go in order to help her in a way that I don't cross lines with what I'm gonna be saying. That I can give her that support that she needs but also doing my job. So, by working with all of them, I was able, we were able to help her, to make her feel like, hey, you know what? You can still fight. You can still manage to defeat this cancer, you just have to put that support that you need. And we were able, I was able to talk to her husband… and a couple months ago, she told her doctor that because of me, because of us, we were able to save her life because now she has her grandbaby and new grandbaby. And now there's another one coming. And now she's fighting to see them grow."—Focus Group Participant 4
	Behavioral/individual: health behaviors and coping strategies		"The patient gets upset when you ask him the same questions every day… They even know it by heart, 'She's going to ask me this. She is going to ask me that.' If he's in a good mood, he's going to answer. But if he is in pain, he feels sick, he had a bad night and couldn't sleep, he's not going to answer your questions. Or he's going to say, I don't feel good. I want to reschedule."—Interviewee 5	Research team - Provide mental health training for CHWs	

Table 2 (*continued*)

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Category	Relevant NIMHD Research Framework domain(s)/level(s) and health determinant	Barriers	Representative quote	Related facilitators by group (CHWs, research team, or healthcare institution)	Representative quote
	Healthcare system/individual: health literacy	Lack of knowledge about CHW scope of practice	“We are not nurses, social workers, or providers. We cannot give medication recommendations. We cannot be their interpreters. We cannot do everything for the patient, our goal is to educate the patient for them to be self-sufficient and manage their own health care needs.”—Survey Short Answer Response	CHWs: - Educate patients about the CHW role and scope of practice and basic cancer education including stages, how pain medication can help, and next steps	“So, for me, the first thing I do is I talk to them a little bit about why they were referred, what my role is… But I really want to know: what do you feel you need help with?”—Interviewee 1
	Sociocultural environment/societal: societal norms	Community stigma and racism	“On… cancer, I really struggle personally because when a member like, our community, when somebody is needing help the most and the community around somewhat understands, but they don’t. And also they kinda look at the person: “Oh you have cancer, you’re gonna die.” That’s how it’s connected… Everybody’s getting ready for you to pass out or something. So it’s just it’s one of those things that really affect the person who’s going through that and the fact that the many people don’t understand and they give you advice and to take all these things and it just turns into a whole thing.”—Focus Group Participant 2	CHWs: - Navigate cultural barriers and strive to integrate culture, family, and patient needs	“But if community health workers are involved in educating the community in a bigger way than that would help the individual, that is going through.”—Focus Group Participant 2
	Sociocultural environment/interpersonal: interpersonal discrimination	- Cultural stigmas about people with cancer	“I also know that some patients feel rejected because they’re a different race. You have to take that into account… A patient told her daughter, ‘Bring me anybody except an African American.’ Yes, she actually told her that. The daughter had to respect her mother’s request. We may be Hispanic, but you know that Hispanics may be White or Black, but she told her, that she didn’t want a Black person.”—Interviewee 5		“It’s important: give support to the family. Very important because the family get tired. It’s not because they don’t love them. It’s because they get tired about the situation, frustrated, and they face also the phases of grief. It’s important to support them, too… Because it’s not the only patient has cancer, it’s the whole family they are facing with that. So, it’s very, very painful. Very sad.”—Interviewee 6
		- Patient preferences to only work with CHWs of a specific race			“Finding a way to bring it all together: the culture and the family with what’s best for the patient, whether it’s the medication, whether it’s the treatment, whatever they may have individually, finding out what’s best for the patient and really take into consideration what they want, what they feel because we have a lot of opinions as family, we have a lot of opinions too with everything, but what does the patient really want?”—Focus Group Participant 1

[†], the NIMHD Research Framework includes example determinants within each cell. These examples are not intended to be exhaustive, thus in two cases we adapted the examples to better fit our results (e.g., instead of ‘patient-clinician relationship’ we used ‘patient-CHW relationship’). NIMHD, the National Institute on Minority Health and Health Disparities; CHW, community health worker.

Discussion

We discuss the feasibility of integrating CHWs as members of a collaborative care team for pain management to support rural-dwelling and/or Hispanic/Latino patients diagnosed with cancer experiencing clinically significant pain via digitally enabled means. We found that, with proper support and training, CHWs would feel comfortable working as members of an interdisciplinary collaborative care team for cancer pain management. The participant-CHWs also identified barriers and facilitators to ASCENT implementation which we categorized into five groups (working remotely in an unfamiliar geographic area, resource availability, technology, implementation-specific challenges, and patient-level factors) and mapped them to the NIMHD Research Framework.

Most barriers and facilitators were within the healthcare system domain and/or at the individual level. Thus, our mapping of the results indicates that, to feasibly integrate CHWs in collaborative care teams for pain management, the CHWs, medical team, and healthcare institutions need to strive to address issues at all levels. Our results suggest that these changes could lead to the successful implementation of a collaborative care model that includes CHWs and improves pain management for Hispanic/Latino and/or rural-dwelling patients diagnosed with cancer.

Some of the identified challenges will be difficult to tackle including CHWs managing patients remotely through digital means. Our findings suggest this is feasible, but potential barriers include digital access, literacy, and challenges with establishing rapport between CHWs and patients. However, there is also an opportunity for CHWs to access more patients across large geographic areas and dispersed niche populations that would be impractical to reach in-person—a topic that could be further explored in the future using a decentralized clinical trial.

Our data contradicted itself in one interesting way. Few of the CHW participants reported regularly working with patients with cancer (>60% were once per month or less) yet all had confidence working with a healthcare team to help patients manage their cancer pain. These findings may mean that CHWs believe their skills can be successfully applied in the context of many health issues including cancer survivorship care.

The CHW tasks that would facilitate the ASCENT study suggested by the participants aligns with the National Council on CHW Core Consensus (C3) Standards. For example, participants suggested that ASCENT CHWs should ensure patients understand study and care plans which falls under role 2: "providing culturally appropriate health education and information". Also, their suggestion to hire CHWs who are dedicated to helping the community is in line with the C3 finding that 'connection to the community served' is the most critical quality (37). In the future, more research is needed on how the tasks performed by CHWs working in cancer care compare to the C3 Standards.

Our finding that CHWs have the potential to be part of a collaborative care team to support pain management is similar to other research. In two qualitative studies examining CHWs' and healthcare professionals' perspectives on a CHW-led advance care planning (ACP) and cancer symptom screening intervention, researchers found that healthcare professionals deemed the intervention as an acceptable, effective, necessary part of cancer care and CHWs felt they served a crucial healthcare team role (38). The healthcare professionals stressed the importance of CHW training, integrating CHWs as valued team members, and addressing retention to sustain complex interventions (39). Yet the CHWs described needing time to develop trusting relationships with patients, ongoing training on how to discuss sensitive topics (e.g., cancer symptoms), and social and emotional support. They also found that communication between the CHWs and the oncology team could be challenging and that power differentials impeded high quality care delivery (38). The participant-CHWs in our study also identified these factors as potential barriers, reinforcing the need to proactively address these issues in ASCENT.

Initial time and resource investments to address these barriers so that CHWs feel comfortable and supported working with patients with cancer pain as part of a collaborative care model may not only provide substantial patient benefit, but also reduce healthcare resource utilization and costs. For instance, the Patient Care Connect Program (PCCP) prioritized older Medicare beneficiaries with cancer and aimed to improve healthcare and lower costs by integrating patient navigators into care teams (40). Researchers observed significant reductions in resource use and costs (e.g., hospitalizations) for PCCP compared to matched non-navigated patients. They estimated the PCCP had a potential 1:10 return on investment which could further justify the sustainability of such interventions (41).

Strengths and limitations

Strengths of this work are our inclusion of the perspectives of experienced CHWs. The participant-CHWs applied their extensive knowledge of the field and provided critical insights. Also, the use of mixed-methods design facilitated a deeper understanding with actionable solutions. Because ASCENT will be implemented in facilities with broad catchment areas in four states, we strove to recruit across the Mayo Clinic enterprise. Unfortunately, we were only able to recruit participant-CHWs in Florida and Minnesota. Our findings should be considered within this context. Additionally, our small sample size limits the generalizability of our findings. Our results do not represent the entire spectrum of experiences or perspectives. Additionally, rapid qualitative analysis has inherent limitations including lack of depth in interpretation and potential researcher bias (42). Finally, the survey and interview/focus group questions were not informed by a specific theory or model and was limited to understanding the feasibility of delivering key elements of the intervention. However, we utilized the NIMHD Research Framework to organize our findings.

Conclusions

CHW interventions are effective at improving outcomes such as cancer screening and health behaviors. Our findings suggest that CHWs can also contribute in meaningful ways to supporting patients diagnosed with cancer as members of a collaborative care team to manage pain remotely, but more research is needed to understand the relative effect compared to collaborative care models alone. As CHWs become more integrated into care teams, we encourage policy makers to expand CHW reimbursement models to include cancer survivorship.

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Footnote

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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 Mayo Clinic Institutional Review Board (No. 23-001838) and informed consent was obtained from all individual participants.

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