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Community health workers supporting emerging adults with sickle cell disease

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A B S T R A C T

Background: Community health workers (CHWs) are vital links between communities and health systems, with CHW models facilitating positive health and life outcomes. However, little is known about CHWs' experiences serving in these roles or their potential to support the transition to adulthood for adolescents and young adults (AYA).

Methods: Semi-structured interviews were conducted with CHWs and their supervisors from five recruitment sites affiliated with Community Health Worker and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS) Trial. COMETS compared the effectiveness of a CHW intervention, mobile health application, or enhanced usual care on the health-related quality of life of AYA with SCD transitioning from pediatric to adult care. To understand CHW and CHW supervisor experiences during the COMETS trial, interviews were analyzed using an integrated inductive and deductive thematic analytic approach.

Results: Three key themes emerged as interviewees described the unique aspects of the CHW role: (1) the supports for transition to adulthood that CHWs provided to patients, (2) the experiences of establishing trusting relationships with patients, and (3) the impact of the role on CHWs themselves. All interviewees reported unique contributions made by CHWs in supporting patients' transition readiness, and CHWs expressed that participating in COMETS impacted them personally and professionally.

Conclusion: This study highlights that the CHW role is unique both in how CHWs connect with AYA and how it impacts CHWs. Health systems should explore paths for sustainable funding and workforce development for CHWs and invest in infrastructure for CHW transition programs.

1. Introduction

Transition to adulthood, the period of time during which young people become young adults as their economic and psychosocial circumstances shift, is especially challenging for adolescents and young adults (AYA) with chronic conditions and disabilities.[1] During this transition period, youth experience major life changes related to employment, education, income, and more.[2–4] Among the health-related difficulties they may face are increasing responsibility for health care decision-making and disease self-management, navigating the ever-changing landscape of health insurance, and often complicated and/or abrupt transfers to adult healthcare.[5,6] While guidelines and best practices for transition to adult healthcare are well documented,[1,7] poor coordination among institutions and lack of preparation for transfer to adult-serving institutions among youth with chronic conditions and disabilities are common.[4,8,9] Several models exist to address the range of challenges associated with transfer to adult care, including care coordination services, educational programming, and shared pediatric/adult clinics.[10,11] However, the extent to which these models effectively address the diverse needs of transitioning youth remains an ongoing area of study.

For young people living with sickle cell disease (SCD), the period of transition to adulthood is a particularly important period.[12] Emerging adults with SCD experience an increased risk of mortality during this

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period[13] and experience high rates of emergency care and hospitalizations.[14,15] Supporting AYA in developing the knowledge, skills, and self-efficacy to take greater responsibility for their own selves and health during the years leading up to, during, and after officially transferring to adult care can play a critical role in promoting positive health and life outcomes. Improving disease-specific and healthcare knowledge, planning for work and/or school, developing habits for disease self-management, and learning to navigate healthcare systems independently are all purported to improve 'transition readiness',[16] meaning that AYA are better prepared to effectively manage their conditions and utilize adult health care services upon transferring their care from pediatric to adult-serving institutions. Existing programs targeting successful transfer to adult healthcare and transition readiness for AYA with SCD, including specialized visits or clinics[17,18] and online education,[19,20] have shown success. However, there is still a need to adapt and expand these programs to better address the systemic and personal challenges that many AYA with SCD encounter during the transition period.

Community health worker (CHW) programs are a promising model for supporting patient populations with higher levels of needs, including those who are medically complex or socially vulnerable, and for assisting with other transitions, such as hospital-to-home care. CHWs are non-clinicians who provide one-on-one support to patients in various ways, including self-management, psychoeducation, treatment plan adherence, and patient advocacy.[21] CHWs also typically come from the local community and share common cultural and social backgrounds with their patients, which allows them to build deep levels of trust.[22–24] CHW models have demonstrated success in improving connections to care and resources,[25] patient experiences,[26] and health outcomes[27–29] for some adult and pediatric populations. Currently, several CHW models exist for patients with SCD,[22] one of which demonstrated improvements in hydroxyurea usage for patients receiving CHW support.[30] However, few programs have implemented CHW programs for transition-aged populations, including young adults living with SCD.[31]

The Individualized Management for Patient-Centered Targets (IMPaCT) model[32] was adapted for the purposes of the Community Health Worker and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS) Trial to train young adults with SCD who have successfully transitioned to adult care to serve as CHWs and support other emerging adults with SCD.[16] The COMETS Trial was conducted across five pediatric institutions, with a focus on improving health-related quality of life among emerging adults with SCD. This qualitative study explores the implementation experiences of CHWs and their supervisors on the COMETS Trial aiming to improve transition readiness among AYA with SCD in order to understand the unique roles of CHWs and their potential to support patients in ways that are distinct from other members of healthcare teams.

2. Methods

Study setting – COMETS Trial.[33] The COMETS Trial is designed to compare the effectiveness of three ways of supporting transitioning youth with SCD: a CHW intervention, a mobile health application, and enhanced usual care. Overall, the COMETS Trial aimed to examine the impact of these supports on health-related quality of life and acute care utilization for patients with SCD who were 17 years old and older with anticipated transfer to adult hematology care within 1 year of study enrollment. Five pediatric institutions across four states in the United States (PA, NY, CT, OH) participated in the COMETS trial.

COMETS CHW intervention. The CHW intervention of the COMETS trial is based on the model developed by IMPaCT Care[32] adapted for use with young adults with SCD with the primary goal of improving health-related quality of life. Adaptations specific to the COMETS trial, tailored to meet the needs of this population, are described in detail in Belton et al.[16] Each of the five participating pediatric institutions hired at least one CHW to work with patients in the CHW intervention arm. In most instances, CHWs had personal or professional experience with SCD, and the study team prioritized hiring CHWs who had successfully transferred their own SCD care to adult providers.

All COMETS CHWs received initial in-depth professional training. The IMPaCT training was 2 weeks for CHWs and 3 days for supervisors. Each additional training, including introduction to the role and scope of work, background on the study population, and introduction to clinical research ethics, were 45–60 min long. CHWs also had access to a tailored job manual, educational materials, and trial-relevant resources, and received regular supervision from both the study team and their respective institutions.[16] The site-specific supervisors (referred to in this paper as "CHW supervisors") were based locally at each health system and acted as the primary supervisory resource for CHWs. CHWs and CHW supervisors met weekly or biweekly for approximately 30 min to review their current caseloads and address any major concerns. A more detailed description of the COMETS supervisory structure and content can be found in Belton et al.[16]

Once a participant was randomized to the CHW intervention, the CHW at their site would reach out to them weekly over a period of 6 months to collaboratively identify and work towards transition-related goals across four main categories: increasing knowledge of SCD and other healthcare information, planning for school or work, developing self-management skills, and navigating healthcare systems and improving self-advocacy. On average, CHWs held a caseload of four patients at a time (range: 0–13), with a total of 122 patients served by CHWs.[16] CHWs were employed by the study on a part-time basis, and their caseloads and weekly hours varied depending on how many patients were randomized to the CHW arm.

Semi-structured interview guide development. To understand the experiences of CHWs and CHW supervisors during the delivery of the COMETS CHW intervention, the study team developed two interview guides, one for CHWs and one for supervisors, with questions tailored to be applicable to the scope of each role. Questions were based on the findings of a brief literature review on CHWs. The literature review indicated that CHWs can help health systems address social determinants of health across a range of care settings, but are often underutilized, undervalued, and lack professional supports.[22,32,34–41] Revisions to the content and structure of the interview guide drafts were made by study leadership as well as CHWs and CHW supervisors. The final guides included questions about the participants' experiences serving as a COMETS CHW or CHW supervisor, including discussion of roles and responsibilities; utility of training, supervision, and supplementary materials; perceptions of personal and professional growth; reflections on the state of the CHW profession, including opportunities for professionalization or expansion of services; and perception of the unique value of the CHW role on healthcare teams (see supplementary materials).

Recruitment and data collection. This qualitative study was granted exemption by the Institutional Review Boards (IRBs) of the Children's Hospital of Philadelphia and Northwell Health. The study team emailed an invitation to all active COMETS CHWs and CHW supervisors (i.e., those who were still serving in their study role) to participate in an interview. Interviews were carried out by two study team members, with one team member leading the meeting and a second team member present to take notes and ensure all questions were adequately addressed. Neither interviewer was a member of the COMETS leadership or supervisory teams, nor had they been involved in the implementation of the CHW intervention. Interviews were conducted and recorded via Microsoft Teams, and transcripts were produced using the Teams auto-transcription function. Transcripts were de-identified and cleaned for accuracy and clarity by members of the study team.

Data analysis. An integrated approach[42] was employed for codebook development, coding, and thematic analysis. Codebook development and coding were led by two researchers with qualitative expertise. The initial codebook included codes defined deductively, or *a priori*, based on study aims and topics covered in the interview guides. Additional

codes were identified inductively based on emerging themes from initial review of several CHW and supervisor interview transcripts. The codebook was further refined through iterative coding and review. Both coders coded two interview transcripts (1 CHW, 1 Supervisor), and met after coding each transcript, using NVivo Release 1's coding comparison query function to review inter-rater reliability. The team resolved coding discrepancies to 100 percent consensus through discussion and made appropriate edits and additions to the codebook. For interviews coded by one coder, coders kept individual memos with notes, questions, and specific interview references that were discussed together, revising the codebook when appropriate. The final codebook was applied to all 11 interview transcripts. A study team member who had conducted interviews reviewed the content from the codes, stratified by role (CHW/Supervisor), and summarized emergent themes and patterns across codes. Several members of the study team collaboratively reviewed and refined the themes and findings as a research consensus check.

Member checking. The study team emailed interview participants to offer the opportunity to participate in member checking of the synthesized findings.[43] Participants who opted in chose to participate in one of two ways based on their preferences – (a) reviewing a written summary of the study methods and findings and offering feedback via email with responses to four prompts about the resonance of the findings with their experiences or (b) meeting with a study team member to hear a verbal summary of methods and findings and discussing the same four prompts. Interviewee feedback informed minor wording adjustments in the results section and yielded a few suggestions for the framing of the discussion section.

3. Results

From May to August 2023, each of the five invited CHWs and the six invited CHW supervisors participated in an interview, with none opting out of participation. CHW interviews were conducted in two parts, lasting approximately 1 h and 45 minutes total (range: 61–115 min), while supervisor interviews were conducted in one part and lasted about one hour (range: 35–69 min). Four CHWs were younger than 35 years old at the time of the interview. All CHWs had some personal or prior professional experience with SCD, and three disclosed an SCD diagnosis. CHW supervisors were all members of the SCD programs at their health systems and had professional and educational backgrounds in social work, psychology, and/or health care transition. Overall, three key themes emerged as interviewees described the unique aspects of the CHW role: (1) the supports for transition to adulthood that CHWs provided to patients, (2) the experiences of establishing trusting relationships with patients, and (3) the impact of the role on the CHWs themselves. The following sections describe key findings related to each of these themes.

3.1. Theme 1: Supports for transition to adulthood

Responses indicated that CHWs were uniquely positioned to aid in the transition to adulthood and improve patients' transition readiness. CHWs were careful to approach their work with patients in ways that centered patients' own priorities and concerns and offered in-depth support in a range of areas. See Table 1 for representative quotes.

3.1.1. Patient-centered approach

Critically, while this CHW role was tasked with supporting patients in the context of transition to adulthood, CHWs did not view their purpose as simply 'checking off boxes' to achieve transfer to an adult hematologist, but instead supporting transition readiness on a patient's own terms. Rather than taking a prescriptive approach to choosing what supports and resources they offered patients to support their transition to adulthood, CHWs sought to support patients in developing the skills, knowledge, and self-efficacy to take charge of their health and increase

Table 1
"Supports for transition to adulthood" subthemes and illustrative quotes.

Subthemes	Summary	Illustrative Quote(s)
Patient-centered approach	CHWs supported their patients in developing knowledge, skills, and habits relevant to transition to adulthood which the patients identified as priorities, while centering patients' growth and self-efficacy.	"I'm coming in […] giving them a little bit more of the space to kind of figure things out and not telling them, 'OK, well, this is what we're gonna do. And let me help you and let's do this'. I'm kind of more like, OK, well, you know, the point of this is really for you to be able to take charge of your own health. And these are the types of things that will be expected of you. […] So I think the way that I kind of approach speaking to them and helping them is a little bit different because they're getting a little bit more of that adult role" (ID 4, CHW)"I know that we spent time teaching them about motivational interviewing and I think that was incorporated in what they did, but I think they did much more than that. And I think they respected the tenets of motivational interviewing, that it's their patient's decision about where to go, but they were able to really engage them on a very meaningful level." (ID 11, Supervisor)
Goal setting and problem solving	Patients identified transition-related goals and roadmaps for attaining them in collaboration with their CHW, and CHWs supported them in working through barriers to making progress.	"Often when we're in clinic, we might say, OK, well, umm, here's a handout that talks about how to, like, remember to take your medicines. […] Where the community health worker was helpful is that they could set specific goals for- with them that said, OK for this next week, let's try to use this one strategy. Let's try to give it our all, see how that works, and see if it feels like something that's feasible for us to do and accomplish. If not, how can we then modify and tailor that goal. […] it was great to […] have someone there to really support and empathize with our participants around the struggles, the challenges, and helping them problem-solve and navigate in a closer frequency." (ID 6, Supervisor)"So we've used their phone calendar, their phone alarm, I've used- sent them apps like one called Medisafe for medication reminders that has helped them. […] I've sent like resources for community-based organizations. If they had any barriers, such as like transportation and things like that for appointments […] I've taught so many participants how to use [telehealth site] and what like, how to save appointments for [telehealth site] to their phone calendar,

(*continued on next page*)

Table 1 (*continued*)

Subthemes	Summary	Illustrative Quote(s)
		set reminders so they won't miss appointments. How to like request medications on there, refills, and how to send messages to the doctor." (ID 9, CHW)
Healthcare navigation skills and support	Patients often shared information with CHWs or approached CHWs with concerns that they did not feel comfortable disclosing to other members of the care team. This allowed CHWs to bridge the gap between patients' needs and clinic resources, as well as encourage and support patients in advocating for themselves.	"I think often our community health workers were sometimes the first people that our families- our, our participants would reach out to […] they come to the community health worker first and say like, you know, I'm actually just like, really not liking my medicine or I feel like it's not doing enough, and then we would help them think about how to talk to their provider about those things. […] sometimes because there's less frequent contact with a social worker or mental health provider or the team, they might feel more comfortable with that day-to-day person than they feel with other members of the team." (ID 6, Supervisor)"So there was this level of like professionalism that they're able to have, but yet this friendliness that they were able to also bring, and because of that, they were able to get certain information that even the doctors can't get out of the patient, you know, different social information that's very critical to health, their own health, and that could be used to like, just put them in the best position possible moving forward." (ID 7, Supervisor)

independence in patient-identified areas of focus (e.g., applying to college). As one CHW explained, "the point of this really was to teach them and encourage them to take charge of their own health and their life surrounding their health" (ID 4, CHW).

3.1.2. Goal setting and problem solving

CHWs guided patients in identifying transition-related goals motivated by a patient's own strengths and areas for improvement. Interviewees described the importance of a CHW and a patient collaboratively deciding on the specific steps they would take over time to reach those goals and supporting patients in navigating barriers they encountered along the way. CHWs and supervisors explained that CHWs leveraged existing educational resources and tools, the COMETS CHW job manual,[16] and skills they learned from training to guide goal setting while prompting patients to take the lead on identifying what was important to them.

CHWs and supervisors discussed how CHWs collaborated with patients to set goals in areas including building habits for managing their health (e.g., adhering to medication regimens, drinking enough water, monitoring emotional wellbeing), planning for work and school (e.g., seeking disability accommodations, researching scholarships and financial aid for college), and navigating health systems (e.g., preparing for their first appointment with an adult provider, ordering medication, scheduling appointments). One supervisor described how CHWs were able to work with patients to identify goals and pivot in real time:

"Often when we're in clinic, we might say, OK, well, umm, here's a handout that talks about how to, like, remember to take your medicines. […] Where the community health worker was helpful is that they could set specific goals for- with them that said, OK for this next week, let's try to use this one strategy. Let's try to give it our all, see how that works, and see if it feels like something that's feasible for us to do and accomplish. If not, how can we then modify and tailor that goal" (ID 6, Supervisor).

3.1.3. Healthcare navigation skills and support

CHWs and supervisors alike indicated that patients often contacted their CHW before others on the care team with questions or concerns because they were the individual with whom the patient felt the most comfortable. In these situations, CHWs expressed that they were not permitted to give direct health advice but could connect with other members of the care team (e.g., social workers) for follow-up or resources. For example, one CHW described a situation where a patient shared about difficulties at home that, although not directly health-related, were impacting their ability to take care of themselves. The CHW was able to connect the patient with other members of the care for immediate assistance. A supervisor shared how the care team was able to provide higher-level support to a patient when CHWs shared information about larger issues that patients were experiencing that were beyond their own scope of work (e.g., housing insecurity, school advocacy, securing transportation to appointments).

CHWs were also able to prepare and empower patients to advocate for themselves. CHWs reported offering encouraging words, suggesting relevant resources, helping patients develop a plan to communicate their preferences to their providers and families, and even being present for three-way calls with patients and providers.

3.2. Theme 2: establishing trusting relationships

CHWs and supervisors described the uniquely trusting relationships between CHWs and patients as fundamental to their work together and a defining feature of the CHW role. They identified several factors that contributed to CHWs' ability to cultivate trusting relationships with patients in ways that were distinctive from other members of the care team, including their approach to outreach, topics of conversation, and their ability to empathize with patient experiences. The strength of CHWs' relationships with patients was critical to informing and facilitating their collaborative work; without this foundation, interviewees expressed that CHWs would not have been effective in the role. See Table 2 for representative quotes.

3.2.1. Outreach flexibility and consistency

Interviewees highlighted that the structure of the role allowed CHWs to dedicate more time and attention to each patient than other clinical professionals (e.g., nurses, social workers) could. Interviewees described the importance of offering flexibility for patients in both communication methods and timing, especially while serving a younger population who may prefer texting and often have variable schedules due to work and/or school. CHWs connected with patients at different times of day and over a range of mediums, including via video calls, text messaging, and phone calls, often leveraging different methods of contact to offer varying levels of support (e.g., brief check-ins by text vs. longer phone calls to set goals). CHWs were also very willing to reschedule planned meetings as needed to accommodate patients' schedules.

While CHWs were required to reach out to patients at least once a week, they reported more frequent contact with some patients. Even when patients did not respond, CHWs continued to make weekly outreach attempts, and all CHWs reported that this dependability was critical to building trust and supporting patients' success.

3.2.2. Building rapport

Alongside their outreach strategies, CHWs expressed that

Table 2
"Establishing trusting relationships" subthemes and illustrative quotes.

Subthemes	Summary	Illustrative Quote(s)
Outreach flexibility and consistency	CHWs connected with patients frequently using a range of outreach methods, and at times and days of the week that were convenient for patients.	"I also think that [CHWs'] availability to just text and communicate in that way with the participant versus, you know, myself being a psychologist, like, we're not able to send texts and you know, we're really discouraged from sending emails and communicating in in these ways that we know tend to be actually a lot more efficient for patients." (ID 1, Supervisor)"[…] it's definitely beneficial, like in the beginning you were like, Oh my God, I have to keep reaching out to them, even if they're not answering? But over time, you just realize it does make a difference […]" (ID 9, CHW)
Building rapport	CHWs employed a range of strategies to help patients feel more comfortable opening up to them.	"I think when it comes to knowing how to offer a resource, or offer, just being a listening ear. Like sometimes umm our job is to be like, find help, find solutions or point in the right direction. But sometimes somebody might just need a listening ear. So, knowing when to give- or point in the right direction when it comes to advice or when to just be a listening ear, be a soundboard for that person." (ID 10, CHW)
Shared diagnosis	CHWs with SCD described ways that their own experiences with navigating transition, self-management, and stigma were valuable in connecting with patients.	"I think being able to connect with them on that level, like, I am not only a CHW but I also [have] sickle cell, I have experienced similar things, even though I cannot, you know, exactly know what you're going through. But I can, you know, definitely like it resonates on a similar level. And I think that they were able to kind of relate to me definitely a little bit more than like I would have with someone who necessarily didn't have sickle cell or maybe like wasn't as integrated into the education of sickle cell." (ID 3, CHW) "[…] use [your] experiences as a positive way of navigating this position, but [don't] let it overshadow this position and […] understand that your experiences are your own and that someone may be in the same situation with you and have a completely different experience than you. […] be ready to do some research and find resources that help people that are having experiences that you've never dealt with and you've never experienced." (ID 4, CHW)
Additional lived experiences	There were multiple aspects of CHWs' identities and life experiences that facilitated trust-building with patients.	"…they're also patients who came out and specifically told me that, you know, I'm- thank God, like there's a black person here and you understand kind of more what we're going through than some of these other people. They don't really, you know, even if they may be really nice and they may be really helpful, they don't really, truly understand some of our lived experiences." (CHW, ID 4)"I've been taking care of myself for a long time since I was younger and then I have a child and then like younger sisters and things like that. So I'm like, I'm so used to like, helping and supporting people. So I think that like really impacted me being able to support the constituents and participants that are younger, that kind of made me feel like a big sister or like a big cousin to them. So just being able to understand the difficulties and the things that they may experience and knowing that they need someone outside of their parent to be able to support them, but also listen to them […]" (ID 9, CHW)

intentionally building rapport with patients was critical to their ability to be effective in this role. CHWs sought to create an environment where patients felt comfortable sharing about a range of topics, including their interests and aspirations, home and social lives, and experiences with healthcare. Most CHWs described building rapport by actively listening to patients and allowing space for patients to discuss things in their lives beyond their health and SCD; something other roles on the healthcare team were less often, if ever, able to offer patients in the scope of their own roles.

CHWs and supervisors also emphasized CHWs' ability to listen intently to patients' experiences related to their SCD and health and validate their struggles while celebrating their successes. By listening without judgment and providing emotional support, CHWs were able to establish a sense of safety that prompted patients to share details of their day-to-day lives and habits that they would not typically share with healthcare professionals (e.g., after-school activities and family dynamics). Thus, the role's defined focus on rapport and relationship building with patients enabled CHWs to gain a deeper understanding of patients' strengths, motivations, and barriers to achieving their goals while staying safe and healthy. As one supervisor elaborated: "[…] they were able to get certain information that even the doctors can't get out of the patient, you know, different social information that's very critical to health, their own health, and that could be used to like, just put them in the best position possible moving forward" (ID 7, Supervisor).

3.2.3. Shared diagnosis

Many CHWs and supervisors described the value of CHWs' personal experiences with SCD in cultivating trusting relationships with patients. CHWs who had SCD were encouraged to decide for themselves whether to self-disclose their diagnosis; however, interviewees felt that CHWs sharing their own experiences with SCD care helped patients feel more comfortable and understood. As one CHW explained, "I do think the relation to sickle cell was really important for the role that I held. And I think a lot of my participants were able to kind of like, reflect on what that means for them. And then we could come together and have a really good, like, conversations about it" (ID 3, CHW).

Even when they did not disclose them to patients, CHWs were able to

leverage their own experiences related to SCD, including navigating transition, self-management, self-advocacy, and specific health systems to relate to and validate patients' experiences and offer a uniquely informed perspective in navigating a range of situations. Despite highlighting the value of drawing on their experiences with SCD when connecting with patients, all three CHWs with SCD emphasized that it was important to avoid assuming that their own experiences would align with those of their patients and to take the time to learn about each patient as an individual:

[…] use [your] experiences as a positive way of navigating this position, but [don't] let it overshadow this position and […] understand that your experiences are your own and that someone may be in the same situation with you and have a completely different experience than you. […] be ready to do some research and find resources that help people that are having experiences that you've never dealt with and you've never experienced. (ID 4, CHW)

3.2.4. Additional lived experiences

Beyond sharing a SCD diagnosis, additional aspects of CHWs' lived experiences and identities played a role in their ability to connect with patients. Some CHWs reflected on how their own family dynamics informed their approach to connecting with patients. For example, two CHWs explained that their experiences as caregivers helped them understand patients' perspectives and emotional needs. Several interviewees described the importance of CHWs' racial and cultural identities in cultivating trust. Within SCD care teams and clinics where staff's racial and cultural backgrounds may differ from those of their patients, the shared identities between CHWs and patients were identified as valuable facilitators of comfortable interactions and stronger connections. One supervisor explained:

I think the fact that our CHW […] was also a black female, I think that allowed, just from the get-go, a lot of defenses to be lowered, a lot more of that relatability and that rapport building to be established. […] our CHW came from an African background specifically so many of our patients who also had an African background and culture really felt like she understood where they were coming from, especially when they talked about family factors or illness perception and other cultural considerations when we think about managing our chronic illness. (ID 1, Supervisor)

3.3. Theme 3: impact on CHWs

Interviewees also shared a range of ways that CHWs themselves were impacted by their time in the role. CHWs primarily reflected on positive emotional impacts and professional development in the role. They also shared challenging experiences. CHWs with SCD described particularly meaningful reflections regarding the positive impacts of their time in the role. CHWs and supervisors shared important considerations for the development, effectiveness, and sustainment of future CHW interventions. See Table 3 for representative quotes.

3.3.1. Emotional impact

As a result of the in-depth, intimate nature of the CHWs' work with patients and their desire to be effective in the role, CHWs reported having experiences that affected them emotionally. These included learning about patients' struggles at home, failing to make contact with patients despite making consistent outreach attempts, and being unable to continue working with patients after the 6-month intervention period had concluded. CHWs described learning about patients' negative experiences as being particularly difficult, especially when they felt that they had failed to prepare the patient to successfully navigate challenging healthcare encounters, or when they felt that they were unable to intervene to improve patients' circumstances. Supervisors highlighted that they regularly supported CHWs through negative feelings when patients were not responding to outreach attempts: "So it was really kind of keeping the community health worker to understand like […] by you

Table 3
"Impact on CHWs" subthemes and illustrative quotes.

Subthemes	Summary	Illustrative Quote(s)
Emotional impact	CHWs were affected emotionally by a range of challenges related to their interactions with and empathy for patients.	"So for my particular [CHW], she actually, she kind of took nonresponse like personal in a sense […] Like, I'm doing everything I need to do and they're just not responding […] She was excited to play this role, and you know, so it was when she wasn't able to do that based on what she, you know, when she wasn't able to make contact […] she would grapple with her value as a community health worker with a non-responsive patient." (ID 2, Supervisor)"[A]nother thing that was- that affected me and was really frustrating to me is I'd never felt like I had enough time with the participants. So the six months would come and go so quickly and there were some participants that I felt like could still use my help and maybe we were in the middle of a goal and now I kind of had to be like, OK, well, we're done here […] And then for the participants that I had a more difficult relationship with or difficult time kind of establishing that rapport, I felt like I didn't have enough time to give them the space to open up and then actually get to whatever it is that they might have needed some assistance with." (ID 4, CHW)
Unique impacts on CHWs with SCD	CHWs who had a SCD diagnosis themselves were particularly impacted by their time working with young adults with SCD.	"I actually would like to stay in this type of role and in this capacity, well, I have been enjoying helping other people with sickle cell. And I think sickle cell is one of those diseases that tends to get pushed to the back and not really discussed and a lot of people are ill-informed. And so my role has not only helped me be able to help others at our specific hospital, but also to be able to help others nationwide. So I've gotten opportunities to speak on medical panels and things like that because of the work that I was doing with COMETS about sickle cell and about transitioning to adult care." (ID 4, CHW)"I think it equipped me to see what I'm capable of. Like just outside of, ohh, I'm someone who has sickle cell and have experience so I know how to like talk to people who have the same thing, but it kind of like gave me tools when it comes to just navigating and talking to anybody who might be transitioning to adult care or anybody in [hospital

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Table 3 (*continued*)

Subthemes	Summary	Illustrative Quote(s)
		system] who might be an adult and who might need a listening ear or just understanding when it comes to the healthcare system." (ID 10, CHW)
Personal and professional development	CHWs grew meaningfully as individuals and professionals through COMETS.	"My community health worker and I have an amazing relationship. So I think that I just like inherited a mentee for a life, like we will continue talking and I will continue doing anything that I need to support their professional development and going forward after the study they had a particular contract deadline time and I helped them apply for jobs as a community health worker. I helped them like to continue pursuing experiences that were relevant after the study was over, and so I- my hope is that I will be in a position as a faculty member that I can continue to do that and support community health workers." (ID 6, Supervisor)"[I]t just made me proud that I was able to help somebody- to get through with somebody, you know, that needed help […] it's always a challenge trying to get through to somebody, but when you get that, that feeling done that you've attained something and you have this person to meet his goal and stuff. It's a good feeling." (ID 8, CHW)
Support for CHWs	There are a range of considerations at the institutional level that are necessary to support the success of the CHW role.	"[…] you do have to fight a little bit against systems to advocate for your worth and your value and what you bring to the table. And that was consistent stories that I was also hearing from community health workers that sometimes their positions were not always secure and they had to really look really hard to find opportunities to be able to apply their skill sets and get paid for it[…]" (ID 6, Supervisor)"I think finding a way to build more community amongst community health workers would be super important, cause it, it could be challenging feeling like they're working in a silo, and knowing that you have individuals that you could rely on that are also doing your role, I think it would be super important. So I would love to see Community health workers be able to interact with other community health workers, cause it's certain things that you could offer one another that you can't be offered if you're talking to your doctor or your nurse practitioner or the administrator, etcetera." (ID 7, Supervisor)

taking the steps that you're supposed to take […] you've met your responsibility. And anything outside of that, it's like, yes […] you want to, you know, be effective and be helpful and all these things. However, you can't make the participant want to engage with you" (ID 2, Supervisor).

3.3.2. Unique impacts on CHWs with SCD

CHWs with SCD frequently reflected on particularly deep connections and impacts from their time in the role. They all reported unique benefits of working with young adults with SCD approaching transition, including an enhanced connection to the sickle cell community at large and the opportunity to reflect on, process, and translate their own experiences with disease management and transition to support others. Two CHWs shared that the role gave them a sense of purpose at a time when they were coming out of particularly difficult periods in their lives. Those same CHWs described the role as providing a space to engage with advocacy for SCD patients and expressed a desire to continue that connection and advocacy beyond this role. Further, all CHWs with SCD indicated that they wanted to continue in the CHW role moving forward, with one CHW saying that their time on the trial solidified their interest and expertise in working with SCD and transition-age populations.

3.3.3. Personal and professional development

CHWs reported developing both personally and professionally during their time working in this role. CHWs described being highly invested in patient success in part because of the close personal relationships they built, and all CHWs reported a sense of personal fulfillment when they were able to connect with patients on a personal level and support patients in attaining their goals.

For several CHWs, this role was the first time that they had used platforms like Outlook, Zoom, and Teams in a professional context. They also described learning about the CHW profession for the first time and recognizing it as a potential career path. For those who hoped to pursue CHW positions after their time in this role, interviewees highlighted the certification received upon completing IMPaCT training as a useful formal credential. CHWs and supervisors also highlighted their close working relationships with one another, and several supervisors expressed the importance of providing career guidance and mentorship to CHWs beyond their day-to-day patient-facing work.

Support for CHWs. Supervisors and CHWs identified multiple components of this role's infrastructure within the COMETS trial that were critical to supporting CHWs' success: formal CHW training, one-on-one supervision, and regular opportunities for reflection and problem-solving with other COMETS CHWs. CHWs cited their supervisors and CHW peers as important resources in working through emotional and workflow challenges.

Supervisors and several CHWs also highlighted that beyond the structure of the COMETS trial, many of their healthcare institutions had less recognition and supports for CHW roles and the CHW profession as a whole. Supervisors, all of whom had extensive educational and professional backgrounds in SCD, transition care, and/or disease management, expressed their appreciation for the unique strengths, skillsets, and insights that CHWs can bring to the care team. Many interviewees, supervisors in particular, expressed a need for continued advocacy for institutions to hire and support CHWs, particularly in working with SCD and transition-aged populations, and several planned to incorporate that advocacy into their future career paths. As one supervisor shared, "Community health workers have vast experiences but do not have the same cost to a hospital system as maybe having a bunch of psychologists […] so I think we can have a bigger reach if we are advocating for these

types of roles in our systems and so hopefully I can help be a part of that, even if it's just like a little bit" (ID 6, Supervisor).

4. Discussion

This study explored the experiences of CHWs and their supervisors delivering a novel intervention aiming to support transition to adulthood for emerging adults with SCD. To our knowledge, this is the first study to investigate the role that CHWs can play in improving the transition readiness of patients with SCD. The findings highlight the valuable transition supports CHWs offered to patients as well as the unique strengths of CHWs' trusting relationships with patients, which were often facilitated by shared lived experiences. These findings also underscored how serving in the CHW role impacted CHWs themselves, raising the importance of infrastructure to support CHWs as professionals and advocacy to sustainably implement CHW roles within health systems.

The role COMETS CHWs played as a part of the healthcare team was frequently described as distinct from other roles (e.g., physicians, social workers) by both CHWs and supervisors. The patient-centered nature of the role along with the frequency and flexibility of outreach enabled CHWs to build strong connections and rapport with their patients. Trusting relationships between CHWs and patients facilitated collaborative goal setting and defining small, achievable next steps for patients and their CHWs to work on together over time. These close, ongoing connections often resulted in patients reaching out to the CHWs more frequently than others on the healthcare team with health-related questions, allowing CHWs to facilitate connections for patients back to their providers. Programs in other settings have also demonstrated the unique role CHWs can play in improving resource connections,[25] health outcomes,[27] and patient experiences with the healthcare system.[26] For youth and emerging adults in transition to adulthood, especially those with SCD, transition is a time of high risk for disconnection from healthcare and poorer health outcomes.[12,14,15] By providing ongoing and personable goal-oriented support to patients outside of the clinical setting, COMETS CHWs were able to support patients in this population to engage with their health care and improve their transition readiness with a consistency not typically feasible for other roles on the healthcare team.

The value of shared lived experiences between CHWs and their patients was particularly salient in these findings. Existing CHW models as well as other types of peer support models frequently underscore that shared experiences, geography, and identity are powerful tools for supporting populations at high risk of poor health and social outcomes.[44–47] Several CHWs disclosed their own SCD diagnoses and transition to adulthood experiences during the interviews and with their patients. CHWs and supervisors also discussed other aspects of lived experiences that informed how CHWs related to and connected with patients, such as experiences with caregiving and similar social experiences. These shared lived experiences helped CHWs deeply understand and empathize with patients and truly meet patients where they were, both physically and emotionally. While other roles on the healthcare team have opportunities to connect and empathize with patients, CHWs are uniquely positioned to do so and are often specifically tasked with drawing upon shared lived experiences to forward their work. For the COMETS study, at the intersection of transition to adulthood and SCD, CHWs and supervisors highlighted that CHWs' own experiences with chronic illness and transition to adulthood as well as racial concordance between CHWs and patients were key facilitators in demonstrating genuine understanding of patients to be able to build trust and offer concrete supports for transition.

Serving in this CHW role also meaningfully impacted CHWs personally and professionally. CHWs frequently reflected on the sense of accomplishment and satisfaction they felt when working with patients and seeing patients progress toward goals over time. CHWs with personal SCD experience described how their time in this CHW role challenged them to reflect on their own transition and healthcare experiences in productive ways that enabled them to meaningfully connect with others in their community. Similar findings have been reported regarding the benefits of serving in a peer CHW role to the CHWs themselves, including the opportunity to process some of their own experiences, develop connections with others in the community, and acquire new professional skills.[46]

CHWs and supervisors also underscored that close relationships between CHWs and patients, especially when involving shared lived experiences, had the potential to impact CHWs emotionally when patients were experiencing hardships or were lost to follow-up. Burnout and vicarious traumatization are growing concerns among many health professions,[48–51] and risk to workers' mental health is greater in work environments with high administrative burdens, excessive workloads, low workplace social support, fewer resources, high patient demands, and emotionally charged situations.[52,53] There is also evidence that the risk of vicarious traumatization is greater for peer-informed support workers. In line with other research findings, frequent contact with and mentorship from CHW supervisors and ongoing opportunities to connect with CHW colleagues were crucial to support COMETS CHWs in identifying and processing work-related problems and the emotional impacts of the role. For several CHWs, given their proximity to their own transitions to adulthood, this role was one of their first professional experiences; thus, supervisor support and mentorship were especially critical. Other research also supports the claim that the strong longitudinal relationships CHWs build with patients may improve CHWs' job satisfaction.[54,55]

4.1. Clinical implications

This study draws attention to the types of support and infrastructure needed at the program and institutional levels to implement a CHW program. Some CHWs and many CHW supervisors highlighted a need for greater visibility and sustainable support for CHWs at an institutional level. While the COMETS study provided ongoing opportunities for connection between CHWs across sites, at their own health systems, only a few knew of CHW roles in other programs, and opportunities for peer-to-peer connections were limited, if present at all. Additionally, many supervisors noted that opportunities for paid CHW roles outside of time-limited research projects as well as career advancement pathways for CHWs were not well-defined. CHWs' connection to the communities their patients come from has been identified as one of their most important attributes, potentially leading to health systems prioritizing this background over factors like formal education and job experience. Since these factors heavily influence salaries and promotions, CHWs often have low compensation and a lack of professional growth opportunities within the field.[24] It is important that health systems do not undervalue the critical knowledge and perspectives that CHWs bring to the care team, and structure the roles accordingly. For programs and health systems implementing CHW roles in transition to adulthood where, like the COMETS CHW role, CHWs are often young adults themselves and new to the workforce, role sustainability and career advancement opportunities are even more crucial. Access to sustainable funding is frequently cited as a barrier to hiring permanent CHW roles and offering higher salaries.[24,55] While there is a need for continued advocacy to support the financial sustainability of CHW programs, one promising avenue is Medicaid State Plan Amendments (SPAs) to promote professional licensure for CHWs and authorize reimbursement for services provided by CHWs.[56–59]

Limitations. This study had several limitations. First, only COMETS CHWs who were still in the role at the end of the clinical trial were interviewed, and the findings may not represent the range of COMETS CHW experiences, especially negative experiences, which may have prompted CHWs to leave their positions. Our sample size was also limited, with the CHWs and supervisors employed at five sites located in the northeastern and midwestern United States. Finally, these data

represent the perspectives of those delivering the COMETS CHW intervention, CHWs and their supervisors; patient perspectives are not included nor are outcomes data from the COMETS trial. Further analysis of patient-level and intervention-level outcomes is necessary to provide evidence of the effectiveness of CHWs in supporting transition readiness for emerging adults with SCD. Analysis of patient and trial outcomes will be included in future publications.

5. Conclusion

This study presents an analysis of the experiences of CHWs and CHW supervisors delivering a CHW intervention for transition to adulthood that prioritized hiring young adults with chronic illness or other shared lived experiences to serve in CHW roles. The findings highlight the valuable, reciprocal nature of the COMETS CHW role on multiple levels, underscoring important considerations for implementing, supporting, and sustaining CHW roles within health systems. CHWs built trusting relationships with patients and served as role models and facilitators of successful transition to adulthood. In turn, CHWs, especially those who were young adults themselves, gained valuable professional skills and experience as well as a deep sense of satisfaction in serving their community. Supervisors provided important job-focused guidance and emotional support for CHWs, and CHWs helped supervisors better understand and support the complex reality of patient experiences. With proper attention to training, ongoing support, and sustainability, CHW programs are both a valuable pathway for career development for young adults with chronic illness and a promising model of support for patients through the high-needs time of transition to adulthood.

CRediT authorship contribution statement

Katherine Wu: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation. **Brahadesh Sivakumar:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Caren Steinway:** Writing – review & editing, Supervision, Project administration, Methodology, Conceptualization. **Sadie M. Butcher:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Tanisha D. Belton:** Writing – review & editing, Supervision, Project administration, Conceptualization. **Kim Smith-Whitley:** Writing – review & editing, Conceptualization. **Symme W. Trachtenberg:** Writing – review & editing, Validation, Conceptualization. **Sophia Jan:** Writing – review & editing, Supervision, Project administration, Conceptualization. **Desireé N. Williford:** Writing – review & editing, Supervision, Methodology. **Toyosi Oluwole:** Writing – review & editing, Project administration, Investigation, Formal analysis, Data curation.

Ethical statement

We attest that this work has been carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and is aligned with the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals.

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Declaration of Competing Interest

Kim Smith-Whitley initiated this project as a full-time Perelman School of Medicine University of Pennsylvania employee and Director of the Comprehensive Sickle Cell Center at Children's Hospital of Philadelphia. She transitioned to Professor Emeritus and Physician Affiliate at CHOP in May 2021 with employer Global Blood Therapeutics and in September 2022 with employer Pfizer. All other authors declare that they have no conflict of interest, including affiliations with or involvement in any organization or entity with any financial interest or nonfinancial interest in the subject matter or materials discussed in this manuscript.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.hctj.2024.100091.

Data availability

The data that has been used is confidential.

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