



Training young adults as community health workers specializing in pediatric to adult health care transition to support emerging adults with sickle cell disease

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ABSTRACT

Background: Transition to adulthood is a vulnerable time for emerging adults (16–25 years of age) with sickle cell disease (SCD), as there is a seven-fold increase in mortality rates during the transition period. Emerging adults with SCD also have the highest rates of hospitalizations, emergency room visits, and hospital readmissions compared to other age groups. Community health worker (CHW) programs have been developed to address outcomes such as patient activation which includes an individual's knowledge, skill, and confidence for managing one's health and healthcare, quality of life, and healthcare utilization for patients with chronic illnesses. However, few programs specifically target transition-age patients with SCD.

Methods: The aims of this study were to (1) create and adapt the existing Penn Center for Community Health Workers IMPaCT model trainings and materials to specifically support CHWs working with transition-age patients with SCD and (2) evaluate the feasibility of this adapted model to improve job readiness of the CHWs and perceived value of the CHWs by patients with SCD. A multidisciplinary workgroup defined specific goal-setting categories and developed a targeted CHW training curriculum. Additionally, the workgroup wrote a job manual including step-by-step guidelines with example talking points and defined an ongoing supervision of CHWs. Measures of implementation and impact on CHW job readiness included CHW training completion, job retention, knowledge evaluation, and patient reported CHW engagement.

Results: 15 individuals completed CHW training with an average employment length of 1 year and 4 months. 7 (47%) CHWs had research experience, 8 (53%) had clinical experience, and 11 (73%) reported SCD experience. On post-training knowledge evaluations, CHWs successfully identified key aspects of SCD, role scope, and research ethics. Patients frequently reported that they reached their goals while working with trained CHWs.

Conclusion: This CHW training program provides a novel adaptation to the evidence-based IMPaCT CHW model to support the needs of youth with SCD during the vulnerable time of transition from pediatric-focused to adulthood-focused healthcare.

1. Background

Due to healthcare advances, youth with special healthcare needs are living longer lives, facilitating the need for a transfer of patients from pediatric to adult healthcare settings, often around ages 18–22 years old.¹ In the years prior to the planned transfer from pediatric to adult

care, starting around age 14, patients and families should receive transition to adulthood services (e.g., building self-management skills) to prepare for the shift to the adult healthcare system and, more broadly, adulthood.^{1–3} This transition is a vital and vulnerable time in young adults' lives as they may face challenges due to changes in social situations, education and employment, in addition to adjusting to a new

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healthcare system.^{2–5} While national guidelines for transition exist¹ with experts agreeing on the core elements needed to facilitate transition and transfer,⁶ there is lack of consensus on best practices for implementation, leaving many transition needs unmet.⁷

Transition-related concerns are especially salient for patients living with sickle cell disease (SCD). Emerging adults (16–25 years of age) with SCD experience a seven-fold increase in mortality rates during the transition period from pediatric to adult healthcare settings.⁸ Furthermore, emerging adults with SCD also have the highest rates of hospitalizations, emergency room visits, and hospital readmissions compared to all other age groups.⁹ While some increase is due to cumulative disease effects and increasing comorbidities, transition programs focused on improving self-management skills are critical to improving health outcomes among this group.¹⁰ Existing SCD transition programs to address these challenges include specialized transition visits or clinics,^{11,12} web-based education,^{13,14} and mentorship programs.¹⁵ While many of these models are relatively recent, several have demonstrated high acceptability and improvements in appointment or medication adherence.¹⁶

Community health worker (CHW) programs have been developed across a wide range of patient populations to address outcomes such as patient activation (i.e. knowledge, skills, and confidence), quality of life, and healthcare utilization.¹⁷ CHWs are non-professionals from the local community, hired and trained by healthcare organizations, to support patients in various ways including, coordinating care, coaching to improve health behaviors, and advocating for patients. CHWs can gain patients' trust and improve their experiences of care while helping to address root causes of poorly controlled chronic disease, which may be useful to individuals with SCD.¹⁸ As CHWs become more routinely used with more standardized training, CHWs can become "professionalized" and a pathway for career development for someone without initial healthcare training. Existing SCD CHW programs aim to improve medication adherence, appointment attendance, caregiver education, and self-efficacy.¹⁸ However, few SCD CHW programs specifically target transition-age patients.

In this article, we describe the development and initial implementation of a training program for a CHW role as a part of a clinical trial specifically targeting the needs of transition-age, emerging adults with SCD through adaptation of the Individualized Management for Patient-centered targets (IMPACT) CHW model. The IMPACT model is one of few rigorously studied CHW models showing effectiveness in improving chronic disease control, mental health, and quality of care while reducing hospital days by 65% among adult populations.^{19,20} In the model, CHWs use motivational interviewing to set a patient-driven, long-term goal, then identify several shorter-term goals and specific plans to help accomplish each goal. Our study aims were to (1) create and adapt existing IMPACT model trainings and materials for CHWs use with young adults with SCD specifically addressing transition and (2) evaluate the feasibility of this adapted model to improve job readiness of the CHWs and perceived value of the CHWs by patients with SCD.

2. Methods

2.1. Development context

The Community Health Workers and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS) Trial aimed to compare the effectiveness of two self-management support interventions, a CHW and mobile health application, versus enhanced usual care and to examine each intervention's ability to improve health-related quality of life and acute care use for transitioning youth with SCD. The study population consisted of patients with SCD aged 17 years and older who were appropriate for transfer to an adult hematologist within 12 months of study enrollment. Eligible patients were recruited at five pediatric sites across the United States through daily screening of hematology appointments and reviews of patient registries. Patients

were followed in the intervention arms for the first six months of the study period. Patients were followed with measures related to health-related quality of life, acute care use, usual source of adult care, patient activation, self-management behaviors, and experiences with the COVID-19 pandemic collected through web-based surveys at baseline, 6, 12, and 18 months. Patients receive incentives for completing surveys throughout the study period: \$50 (baseline), \$75 (6 months), \$100 (12 months), \$150 (18 months). Study enrollment took place from January 2019–December 2022. In the CHW intervention arm, the study team aimed to hire CHWs with personal or professional experience with SCD who had transitioned their own medical care to adult providers.

We held weekly one-hour virtual workgroup meetings to facilitate CHW role and training development from November 2017 – December 2018. Multidisciplinary representatives from all five participating pediatric health systems, including SCD program directors, young adult community stakeholders, SCD and transition program social workers, participated. Representative backgrounds included adult hematologists, clinical psychologists, and pediatricians specializing in hematology, oncology, and internal medicine. First, the workgroup defined the CHW role responsibilities and necessary elements of initial CHW training. Second, the workgroup adapted the supervisory structure and continuing education from the IMPACT model, creating new resources and trainings when necessary. We incorporated feedback from workgroup members into role and training materials on an ongoing basis.

2.2. CHW Role and initial training

The COMETS CHW's defined scope of work included four goal-setting categories – (1) increasing knowledge of SCD and general healthcare information; (2) planning for work or school; (3) improving self-management skills; and (4) navigating the healthcare system and self-advocacy. The CHWs worked with patients for 6 months with several defined phases. The *introduction* phase focused on establishing a working relationship between CHW and patient; the *baseline* phase assessed and addressed critical SCD knowledge (e.g. emergency plan, medication access, etc.); the *goal-setting*, *next steps*, and *check-ins* phases were a cycle where CHWs helped patients set self-directed goals and define clear next steps with weekly check-ins; the *graduation* phase included preparing patients to continue managing their health and transition post-intervention. The *baseline* phase was added to the IMPACT model based on the workgroup's strong recommendation that specific aspects of SCD management and safety be addressed with every patient at the start of the intervention. The 14 concrete steps CHWs were expected to follow to carry out the role are included in Fig. 1.

After defining the scope of work and intervention phases, the workgroup identified necessary initial training topics for CHWs: local hospital and community knowledge; SCD and transition to adulthood education; basic clinical research training; foundational CHW skills and concepts; and trial-specific aims and resources. Descriptions and learning objectives for each CHW training component are included in Fig. 2. External trainings included the onboarding and orientation processes at each local site, Collaborative Institutional Training Initiative for clinical research,²¹ and IMPACT's two-week training course for foundational CHW skills. IMPACT's training course covered the foundational skills in community health work and the core structure of the IMPACT. CHW managers and program directors also attended a 3-day training covering the IMPACT model, supervision structure, and hiring. In addition to the trainings, IMPACT provided a comprehensive manual for each role and a recommended structure for CHW encounter documentation.²² Trainings developed specifically for this CHW program included role introduction and job manual overview; population background (SCD and transition); and introduction to clinical research ethics. Each newly developed training module was 45–60 min long and made available to CHWs as videos online. An online database shared by COMETS Trial staff was used to track personnel details and initiation and completion of each training. To move from "trainee" to "active"

Introduction	1. Research staff notifies you of a new patient and introduces the CHW role to the patient.
	2. Introduce yourself and your role, in-person or by phone.
	3. Maintain boundaries if sharing personal experiences while building trust with the patient.
Baseline	4. Conduct the Meet the Patient interview.
	5. Were gaps in 9 baseline items identified during interview? If so, discuss gaps with Trial CHW Manager and address gaps appropriately.
Goal-Setting	6. Discuss the patient's goals for their health and future using the Meet the Patient interview. Choose a SMART goal to work on together.
	7. If needed, use additional resources and questions in "Goal-Setting Support" under the resources section and/or brainstorm additional people to help support goal-setting with the patient.
Next Steps	8. Decide next steps that can realistically be accomplished in 1-2 weeks. Repeat, rephrase, and offer to write down next steps.
	9. Identify if resources are needed for next steps and help the patient access resources (educational materials, contact info, SW, etc.).
Check-Ins	10. Check in weekly with patients in an encouraging and constructive way. Update the patient on your next steps and assess progress on their next steps.
	11. Identify barriers and readjust next steps.
	12. Document all encounters with the patient.
Graduation	13. Prepare for graduation.
	14. Graduate patients when they have completed the intervention.
Additional Situations	Contacting the clinical team with concerns about physical or mental health, safety, drug/alcohol abuse, sexual health, and other sensitive topics
	Accompanying the patient to an appointment
	How and when you can share patient information
	What to say when you don't know the answer
	Tips for effective communication with patients, providers, and community resources
	Tips for de-escalating and re-focusing conversations
	Plan for re-engagement when the patient isn't responding
	What to do if the patient reaches out after the intervention
	Strategies for maintaining professional boundaries
	Personal reactions to tough cases or challenging encounters
	Talking honestly and professionally with supervisors

Fig. 1. CHW Manual – Overview of Step-by-Step and Additional Situation Guidelines.

status, CHWs had to complete each training component and an online evaluation with multiple choice and short answer questions related to each training topic.

2.3. CHW Tools, supervision, and ongoing education

We adapted the comprehensive job manual from IMPaCT's outpatient CHW manual to provide CHWs with on-the-job support and training for all aspects of the CHW role. We made minor adaptations based on the specific trial logistics to several sections of the manual, including an overview of COMETS trial, job expectations, safety protocols, and supervision structure. A set of step-by-step guidelines for each CHW-patient interaction across the intervention comprised a large portion of the manual. While we adapted the structure from the IMPaCT manual, we created novel content for each set of guidelines, including example talking points for each step to assist CHWs in approaching each topic with patients at the recommendation of the workgroup. Fig. 3 includes CHW guidelines and example talking points found in the

manual for one of steps in the intervention. Also as recommended by the workgroup, we developed detailed guidelines for additional situations outside of the defined intervention phases, often safety or clinical scenarios, to help CHWs manage unpredictable scenarios with their supervisors. An overview of the step-by-step and additional situation guidelines are included in Fig. 1. The last section of the manual included a range of resources CHWs were encouraged to access as needed to support their work with patients. Many of the resources, such as the template for the initial patient intake (known as the "Meet the Patient Interview") and patient handouts with CHW information were adapted from IMPaCT. We created two additional resource sets: (1) a comprehensive set of patient-facing education materials organized by the CHW four-part scope of work and (2) a series of "goal-setting support" documents with example patient goals and guidance on offering high, medium, or low support for patients in achieving those goals.

We defined two types of supervisor roles: CHW site supervisors based locally at each hospital and a centralized CHW trial supervisory team who were responsible for overseeing administrative tasks, supervision,

Training Topic	Source	Objectives
Hospital Onboarding	Local hospital staff	The <i>COMETS</i> Trial has CHWs at 5 different pediatric hospitals. Each site/hospital has its own new employee orientation/onboarding process. <ul style="list-style-type: none"> What do you need to know about where you work?
Welcome Meeting	Trial staff	This is a 1-hour meeting (either by video chat or in-person) with the Trial CHW Manager. The goal of this meeting is to answer the questions: <ul style="list-style-type: none"> What is the PCORI <i>COMETS</i> trial and what is the <i>COMETS</i> CHW Intervention? What is the CHW Scope of Work? What comes next in CHW training?
Population Background: SCD and Transition to Adulthood	SCD Social Worker Transition Social Worker	This is a series of 2 self-directed, recorded lectures to help you start focusing the skills you learn at Penn's training to be specific to the <i>COMETS</i> Trial. The goal of this training is to answer the questions: <ul style="list-style-type: none"> What do you need to know about SCD to maintain appropriate messages? What do you need to know about working with adolescent and young adult patients with SCD and their families, especially as they experience transition to adulthood?
Research	Trial staff CITI online training program	The <i>COMETS</i> Trial is a randomized control trial, and the CHW Intervention is one of 3 arms of the trial. It will be helpful for you to learn about the overall study aims and some details about how the research within this trial is accomplished. The goal of this training is to answer the question: <ul style="list-style-type: none"> What are the basics of research that you need to know in order to carry out the CHW role? Have you completed your CITI certification to allow you to work in clinical research?
Penn IMPaCT CHW Training	Penn Center for Community Health Workers	This is a remote training taught by Penn Center for Community Health Workers. The goal of taking this training is to answer the question: <ul style="list-style-type: none"> What are the critical, foundational skills and concepts you need to know to be a CHW?
Conclusion Meeting	Trial staff	Finally, you'll have a 1-hour meeting (either by video chat or in-person) with the Trial CHW Manager on the specific logistics of the <i>COMETS</i> CHW role. The goal of this training is to answer the questions: <ul style="list-style-type: none"> What does your work/planning look like day-to-day? What tools and supports do you have to help you carry out this role?
Evaluation	Trial Staff	The final online training evaluation has several questions about each training topic to help us understand what you learned at each training.

Fig. 2. CHW Initial Training Components – Source and Objectives.

and ongoing education for all CHWs. Trial supervisors had a background in social work and/or expertise in transition to adulthood. Site supervisors were members of the SCD program at each hospital, often a social worker or psychologist. Trial and site supervisors collaborated closely when supporting CHWs in addressing clinical issues or questions raised by patients, both emergent and routine; planning for safety when CHWs met patients offsite; navigating hospital-specific policies; addressing CHW performance concerns when necessary; and concrete suggestions such as applying for scholarships. The shared online database we created to track onboarding and training progress was also used to document administrative notes and CHW supervision.

The individual and group supervision session structure, based on IMPaCT's model, emphasized ongoing CHW support and education. Individually, each CHW met weekly for 30-minutes with a trial supervisor and their site supervisor to discuss their current caseload and address any major concerns. Collectively, we established monthly cross-site group huddles to support ongoing peer-to-peer learning, networking, and support. These CHW huddles served as a forum for CHWs to teach and learn from one another's experiences, often through presenting and discussing case examples. A supervisor huddle convened monthly with site and trial supervisors meeting virtually to share hiring and onboarding lessons learned, discuss implementation successes and challenges, and offer peer support across sites. Specific professional

development or ongoing education needs for CHWs were identified by the supervisors (e.g., goal setting, maintaining boundaries, etc.). These ongoing education topics were then addressed during the monthly cross-site CHW huddles. Examples of topics covered include, dealing with patient loss and lengthy hospitalizations, supporting transgender and gender expansive youth; and clinical themes such as managing SCD while away at college, managing COVID-19 and preparing patients for the weather impact on patients with SCD.

We used several measures to understand feasibility, implementation, and impact on CHW job readiness of this adapted CHW training model. We tracked (1) the total numbers of CHWs trained, including those who did not fully complete training, (2) the CHWs' results on the training knowledge evaluation, (3) CHW job retention, (4) CHW caseload, and (5) patient reported CHW engagement. Patient-reported CHW engagement was measured via monthly quality assurance (QA) calls conducted with one randomly selected patient per CHW per month. Patients selected were only contacted one time during the study period. During QA calls, patients were asked about their quality of life and any challenges related to their health. In addition, patients were asked if they could identify their CHW by name, the last time they spoke with them, whether they had set and reached specific goals with their CHW, and thoughts or recommendations for improving the program. QA calls also informed ongoing decisions made around continuing education for

8. Decide next steps that can realistically be accomplished in 1-2 weeks. Repeat, rephrase, and offer to write down next steps.

Remember:

- ◆ Goals and roadmaps take time to accomplish! Be sure to celebrate every positive step toward a goal. One step may seem small, but encouraging patients every step of the way makes a huge difference!
- ◆ Be specific! Coming up with specific, small steps that you and the patient can take every week or two can help make a big goal feel more manageable. Each time you talk to a patient, define specific next steps.
- ◆ Everyone learns differently! Give the patient plenty of time to ask questions and talk about any concerns they have about what to do next.

Guidelines	Example Strategies/Talking Points
Talk About Your Next Steps: After choosing a goal to work on, it is really important to come up with some concrete roadmaps for making progress toward that goal. It is also important to clearly state what the next steps are after each check-in with a patient. Sometimes, it is helpful to start the discussion about next steps by talking about what <u>you</u> will do next to help the patient. Remember to include specific details about: <ul style="list-style-type: none"> ◆ What you will do before the next check-in. ◆ When you will check in next with the patient. 	Defining Your Next Steps: What and When <ul style="list-style-type: none"> ◆ <i>What:</i> "I'm glad we're working towards you going to Community College of Philadelphia in the fall! Like we talked about, I am going to search online and find the contact information for their Disability Services Office. I'll also try to find out more about how to request accommodations." ◆ <i>When:</i> "I'm going to find that information in the next week. Then I'll call you next week to talk about what to do next. Does that make sense? Do you have any questions?"
Talk About the Patient's Next Steps: It's really important to define clear, concrete next steps for the patient. Be sure to give the patient chances to ask questions and bring up any concerns they have about their next steps. Remember to include specific details about: <ul style="list-style-type: none"> ◆ What the patient's next steps are. ◆ When you will check in next. ◆ How the patient might be able to accomplish those next steps. 	Defining The Patient's Next Steps: What, When, and How <ul style="list-style-type: none"> ◆ <i>What:</i> "Like we talked about, it can really help to be prepared when going to talk to the Disability Services Offices. Can you try to find a copy of your IEP that you have in high school? Can you also write down a list a ways that your symptoms affect you at school?" ◆ <i>When:</i> "I'm going to ask you about those two things when I call you next week." ◆ <i>How:</i> "You could ask your parents to see if they have a copy of your current IEP. You could also ask your counselor at school to see if she has a copy or knows someone who does. Does that make sense? Do you have any questions?"
Repeat, Rephrase, and Offer to Write Next Steps: Everyone learns differently, so you may have to repeat what the next steps a few times and in a few different ways. This also gives the patient a chance to ask questions. It can also be really helpful for both you and the patient to write down the next steps. You could offer to: <ul style="list-style-type: none"> ◆ Write down what you talked about as well as the next steps and give it to them in-person. ◆ Email the patient what you talked about and the next steps. ◆ Text the patient what you talked about and the next steps. 	Repeating, Rephrasing, and Writing Next Steps: <ul style="list-style-type: none"> ◆ <i>Repeat/Rephrase:</i> "So I'm going to get some info about Disabilities Services for you, and you are going to try to find your IEP and write down some things about your health and school. I'll call you next week to see how we're doing. Does that work for you? If you think of questions during the week, you can call, email or text me." ◆ <i>Writing Next Steps:</i> "I know we talked about a lot. Do you want me to write down some of the things we talked about? Would it be helpful if I email or text you what we are going to do next?"

Fig. 3. CHW Guidelines and Example Talking Points for Step 8 - "Decide Next Steps".

CHWs. These measures of patient reported CHW engagement were used to understand the impact of the CHW training on job readiness (e.g., CHWs with sufficient job readiness would be appropriately engaged with patients and facilitate successfully setting and reaching of goals).

3. Results

A total of 19 individuals were identified for the CHW role in the COMETS Trial to serve 5 large clinical sites, 15 (79%) completed the initial onboarding and training requirements, 2 (10.5%) started the onboarding and training process but dropped out due to school or work plans changing, and 2 (10.5%) individuals did not meet the criteria for the role due to location changes and time requirements. CHWs serving in

this role ranged from 22–70 years old, with a median age of 29 years old. Of those who completed the initial onboarding and training, 7 (47%) had previous research experience, 8 (53%) had previous clinical experience, and 11 (73%) reported SCD experience. Previous research experience included prior job experience working on research studies; clinical experience included previous educational training or work experience in a hospital or clinic setting; and SCD experience included personal or work experience with the SCD population. Personal experience included having family members with SCD.

After completing training, all CHWs were required to complete an evaluation assessing knowledge of training components. Evaluation questions assessed knowledge of the population, clinical research, and the main components of the intervention. CHWs were asked questions

such as “Which of the following are critical Sickle Cell medical issues that need immediate attention?”, “What are the key elements of informed consent?”, and “When should you document...after working with a patient?” Evaluation results showed that 13 CHWs (100%) were able to identify three complications of SCD, 11 (85%) identified the four main parts of the CHW scope of work, and 12 (92%) identified the primary goal of the Institutional Review Board.

For CHWs who were fully trained, the range of employment was four months to three years, with an average length of employment of one year and four months. CHWs in this role were all part-time employees, pay rates were determined by each institution. On average, CHWs held a caseload of four patients (range: 0–13). A total of 122 patients were served by CHWs. Patients were contacted on a weekly basis, most commonly via phone or text message. Goal setting was one of the significant components highlighted in this training program. The most frequent goals set when working with patients included increasing knowledge of SCD and healthcare (25, 30%), increasing knowledge for school and expectations (18, 21%), and improving skills to manage health (27, 32%).

QA calls were conducted monthly while there were active patients in the intervention arm by the trial supervisors, using a prepared script. Supervisors selected one patient per CHW per month. A total of 59 calls were attempted throughout the intervention period, 36 (61%) of the patients were reached, 4 (11%) did not want to participate in the call. Of those reached and interested, 31 (97%) of the patients were able to identify they had a CHW, and 24 (75%) were able to reach the long-term goals identified. Patients were asked about their current health, 11 (34%) reported their health as excellent, 9 (28%) very good, 11 (34%) good, and 1 (3%) reported their health as fair. Patients were asked if they would recommend the program to a friend or family member, on a scale from one to ten, all patients who answered this question (30, 94%) selected a score of seven or higher, with 22 (73%) selecting a ten.

4. Discussion

In this paper, we describe the adaptation of a current CHW model to fit the needs of emerging young adults with SCD. We developed a training and supervisory infrastructure tailored to support CHWs, often individuals with personal SCD experience, in building relationships and setting goals with young adults with SCD to improve self-management skills, increase healthcare engagement, reduce emergency department visits, and improve self-rated health. Additionally, with the support of the multidisciplinary CHW workgroup, we created a set of tools, including a program manual, educational materials, and resources, for CHWs to utilize in their interactions with patients.

The COMETS Trial CHW training program is a unique addition to existing CHW programs. It is structured and based on an evidence-based program, IMPaCT, and focuses on a new population, young adults of transition age. This program focuses on improving self-management skills needed for a successful transition for young adults with SCD. When developing this program, we enhanced the current IMPaCT model by incorporating tools specifically tailored to this new population.

Existing SCD transition programs have demonstrated success through online interactions and education^{13,14} as well as mentorship models.¹⁵ Additionally, existing SCD CHW programs incorporate disease management and knowledge goals.¹⁸ However, few transition specific CHW programs for SCD have been documented. Documenting the development of such a CHW training program is important to demonstrate a combination of existing strategies for meeting the needs of this population of young adults with SCD experiencing a particularly vulnerable period in their healthcare and life. Training materials from IMPaCT for adult populations required adaptation to better prepare CHWs to work specifically with young adults in the pediatric setting and account for many CHWs being young adults themselves. Training and supervision for this program required additional focus on navigating two types of health systems (pediatric and adult), other life transitions

taking place among patients this age, and working with patients along with their families.

Initial implementation of the training program also highlighted unique challenges of hiring and training young adults as CHWs to work with young adult patients. When identifying candidates for the CHW role, we aimed to identify individuals with shared life experiences with SCD and transition to adulthood, often young adults. When recruiting young adults, we noticed a lack of structured work experience, demonstrated in a lack of communication and accountability related to the role. Turnover was a common challenge in this role; a total of four (26%) CHWs left the role during the study period. Reasons included better job opportunities and pursuing higher education. Others experienced challenges with meeting job expectations, and one CHW was terminated. As we were looking for individuals with close experience to the patient population being served, young adults with limited work experience, we learned that we were not communicating performance expectations and goals for CHWs and for each site overall. Due to challenges retaining a young adult CHW at one of the pediatric sites, an exception was made to recruit an older adult (70 years old) with personal experience with SCD. We continue to make improvements to address these issues, such as updating the job description, more in-depth coverage planning, and a more structured performance evaluation plan.

5. Limitations

The development and implementation of this CHW training program had several limitations. First, trainings and protocols focused on CHW-patient interactions were developed prior to the COVID-19 pandemic and included some focus on identifying opportunities to connect with patients in-person. Second, there was limited evaluation of both pre-training knowledge and ongoing knowledge retention after the initial training evaluation assessment. While ongoing training occurred during monthly CHW huddles, there was no systematic evaluation of knowledge gained and retained, highlighting a future opportunity for quality improvement. Additionally, we did not use quantitative data analysis to examine trajectory of change in patient ratings in the QA call items. Future work should assess long-term outcomes associated with CHW interventions and include a comparison group without a CHW. As this data is a part of a clinical trial, analysis of patient outcomes will be presented in a future manuscript.

6. Conclusions

This paper describes the in-depth, collaborative process for adapting an existing, evidence based CHW model (IMPaCT) and training for CHWs to use with young adults with SCD. We adapted and developed training materials not only for initial CHW training, but also for ongoing “on-the-job” support and supervision. Documenting our development process and our observations and lessons learned from implementation thus far may support others working to develop programming for this population or adapt CHW models for other vulnerable populations.

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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.

CRedit authorship contribution statement

Rubin David: Writing – review & editing, Supervision. **Jan Sophia:** Writing – review & editing, Supervision, Conceptualization. **Belton Tanisha:** Writing – review & editing, Writing – original draft, Project administration, Conceptualization. **Wu Katherine:** Writing – review & editing, Writing – original draft, Project administration, Conceptualization. **Steinway Caren M.:** Writing – review & editing, Project administration, Conceptualization. **Trachtenberg Symme W.:** Writing – review & editing, Supervision. **Tchume-Johnson Trudy:** Writing – review & editing. **Shilly Steffi:** Writing – review & editing. **Austin Tahirah:** Writing – review & editing. **Luma Samantha:** Writing – review & editing. **Smith Kyle:** Writing – review & editing. **Smith-Whitley Kim:** Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare no conflict of interest.

Data availability

No data was used for the research described in the article.

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