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Strengthening the community health worker practice

Edited by
Julie Ann St. John, Lily K. Lee, E. Lee Rosenthal
and Durrell J. Fox

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Strengthening the community health worker practice

Topic editors

Julie Ann St. John — Texas Tech University Health Sciences Center, United States
Lily K. Lee — Independent researcher, United States
E. Lee Rosenthal — Texas Tech University Health Sciences Center El Paso, United States
Durrell J. Fox— JSI Research & Training Institute, United States

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Editorial: Strengthening the Community Health Worker Practice

Lily K. Lee[1†‡], Julie St. John[2*†‡], Durrell J. Fox[3†§] and E. Lee Rosenthal[4†§]

[1]KTE Strategies, LLC, Corona, CA, United States, [2]Department of Public Health, Texas Tech University Health Sciences Center, Julia Jones Matthews School of Population and Public Health, Abilene, TX, United States, [3]Health Services Division, JSI Research and Training Institute, Atlanta, GA, United States, [4]Department of Medical Education, Texas Tech University Health Sciences Center El Paso, El Paso, TX, United States

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EDITED AND REVIEWED BY
Christiane Stock,
Institute of Health and Nursing
Science, Germany

*CORRESPONDENCE
Julie St. John
✉ julie.st-john@ttuhsc.edu

†These authors have contributed equally to this work
‡These authors share first authorship
§These authors share senior authorship

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Editorial on the Research Topic
Strengthening the Community Health Worker Practice

The Editorial Team is pleased to release this second Research Topic on Community Health Workers (CHW) to bring forward trends in the field including recruitment, integration, (https://www.frontiersin.org/research-topics/15204/community-health-workers-practice-from-recruitment-to-integration) and now in this issue featuring more analysis of CHW trends in these same areas with an emphasis on: CHW capacity building; organizational and system readiness for CHW integration; championing CHW professionals and preserving the profession; CHW program evaluation and; methods and CHW certification. “Working to strengthen CHW practice” means taking time to hear voices that are often unheard: CHWs and those they serve; contributors often unknown; CHWs and allies; and even potential authors—CHWs and those in practice roles—who have begun to tell the story of their work along with the capable traditional research community of authors presented here. We looked for all of these to be represented in the two issues that comprise this Research Topic. See more about the breadth and depth of this issue in the discussion that follows.

The continuing U.S. healthcare crisis of rising healthcare costs and poor health outcomes have pushed public health and medical systems to seek solutions to address persistent gaps. Studies have revealed the deeper roots of this crisis: medical care accounts for only 20% of the variation in health outcomes for a population, while social determinants of health account for 80% (1). Community Health Workers (CHWs) who have worked for generations as trusted members of the community they serve and as trusted public health messengers, have been a workforce that has served as a focus of attention to address these deeper roots. Research, evaluation, and other reports have documented CHWs’ unique ability to engage with communities and individual community members, facilitate care coordination with health and health-related providers, enhance access to community-based services, address social determinants of health, and provide health education for prevention and disease management. As a result, although CHWs are non-clinical in their scope of practice, CHWs are increasingly integrated into complex health care and managed care plan organizations. States are looking for more sustainable financing mechanisms for CHWs through Medicaid State Plan Amendments (SPAs) and 1,115 waivers, while managed care organizations and health plans are exploring creative incentives to support healthcare organizations to adopt the CHW integrated model (2). Yet, there is very little discussion around the complexities of integrating a traditionally grassroots, community-based, non- clinical workforce into complex clinical workspaces driven by licensure, hierarchy, and strict compliance policies and processes, while protecting CHWs' unique roots and community connections.

This special CHW issue provides a collection of papers addressing CHW capacity building, organizational and systems readiness, championing and preserving the profession, examining CHW program evaluation methods, CHW credentialing opportunities, and other work recognizing CHWs' contributions to improving population health and community wellness. Consistent with the spirit of, "Nothing about us without us," the call sought out papers where CHWs served in direct roles in the projects and programs as well as in the writing as co-authors and contributors of the manuscripts.

Similarly, the editorial team invited CHWs as peer reviewers of the manuscripts ultimately featured in this issue.

Capacity building

CHW workforce capacity building generally involves CHW core training, formal education with college-credits, continuing education covering specific topics, and other professional development opportunities. In recent years, CHWs have also advanced their careers through leadership opportunities in CHW networks and associations, coalitions, alliances, and collaboratives. To further support CHW workforce capacity, CHW programs have also explored their capacities related to financing and sustainability, recruitment and retention, program outcome evaluation and quality improvement. CHW training curricula specifically designed to meet the needs of priority populations have also emerged in recent years. Kitzie et al. present their curriculum and instruction approach to address disparities in the LGBTQIA+ communities. The 30-h LGBTQIA+ specialty training was co-developed by CHWs and researchers with expertise in LGBTQIA+ populaions and health information. The curriculum was "theater tested" and piloted with a cohort of 11 LGBTQIA+ CHWs. Their findings reveal future opportunities to train medical and nursing professionals and staff using a similar pedagogical framework. Jiménez et al. discuss a CHW/R workforce capacity building innovation implemented during COVID-19 pandemic. A partnership between a statewide CHW professional association and an academic research team facilitated the development of community-grounded tools and resources for "rapid decision-making and knowledge sharing" to support CHWs in the field.

Organizational and system readiness for CHW integration

Integration of CHWs into interdisciplinary teams and into leadership positions is not as intuitive as integrating clinical workforce team members, such as nurses or clinical social workers. For organizations and systems who are new to the CHW model, organizational readiness is critical. The following papers discuss approaches to training supervisors and managers, as well as lessons learned around CHWs in leadership roles. Sabo et al. share their continuous work with tribal CHWs known as Community Health Representatives (CHRs). Their paper discusses CHRs and CHR managers' involvements and perceived level of integration within health care teams and the broader public health systems addressing the social and structural determinants of health. They also discuss lessons learned from the COVID-19 pandemic responses in the tribes. Wennerstrom et al. discuss their original research that included a national cross-sectional survey of CHWs working with Medicaid managed care organizations (MCOs). Key findings from this research related to integration of CHWs into MCOS included: 85% of CHWs made referrals; 75% conducted social screenings; 54% assisted with care planning; 52% conducted health screenings; and 49% participated in case reviews (49.3%). Wennerstrom et al. suggest that CHWs' roles in MCOs focus on supporting clinical care and making referrals for social issues and not on community-level concerns. The authors recommend that MCOs ensure that CHWs: have professional freedom to develop community- based solutions; receive equitable compensation; and have promotion opportunities. Jeyakumar et al.'s original research study explored the current functioning and sustainability of Aboriginal Health Workers (AHWs)—core primary healthcare (PHC) providers— of First Nations peoples in New South Whales (NSW) PHC organizations. Results identified five categories of change required to ensure AHW sustainability and retention: community connection, recognition, value, support, and an inclusive health system—with both service and system level factors influencing each change category. The authors conclude that ensuring sustainability of the AHW workforce will require a system-wide paradigm shift that includes holistic health approaches and suggest the need for future studies co-designed with ACCHOs (Aboriginal Community Controlled Health Organizations) to help inform this change.

Championing CHW professionals and preserving the profession

In addition to building CHW capacity and organizational readiness, organizations successful in CHW integration share some common strategies. Success begins with the right recruitment—individuals from the communities they serve with lived experiences who demonstrate key CHW qualities and attributes (3). Several papers discuss identifying champions for the CHW workforce within the organization who understand CHW core competencies and scope of practice, and advocate for the preservation of the CHW profession, creating career pathways, safety and boundaries, and bridging gaps in understanding CHW integrated practice dynamics. In their opinion paper, Masquillier and Cosaert discuss some arguments of CHW integration in health systems, such as an innovation or just an emergency response through the COVID-19 pandemic. In Belgium, the pandemic served as a catalyst that revealed various gaps and disparities in the system, including shortages and unmet needs of socio- economically vulnerable communities. The authors elevate the need to build the CHWs' role in supporting "equitable and accessible healthcare for all, by looking beyond emergency responses." Strengthening the CHW workforce involves formulating a long-term vision and ensuring sustainable funding, both of which were "set in motion by the COVID-19 pandemic." In their original mixed methods research study, Ajisegiri et al. explored CHW roles and practices related to the delivery of non-communicable disease (NCD) services at primary health care (PHC) facilities in four Nigerian states; traditional CHW work in Nigeria has focused on infectious diseases and maternal and child health services. Study findings demonstrated that CHWs frequently delivered services beyond the scope of practice stipulated in the Nigerian National Standing Orders for CHWs; the need to serve the community primarily motivated these informal task-shifting practices. The authors assert that provision of services related to NCDs both partially support health system functions and address unmet needs but could also lead to variable care quality and safety. The authors recommend ways to mitigate potential adverse impacts and to strengthen CHW roles in the health system, including: a stronger enabling policy environment to support NCD task-sharing; investment in continuous CHW capacity building; improved guidelines for implementation at the point of care, and improved coordination processes between PHC and higher-level facilities. In their original research, Smithwick et al. conducted a mixed-method study on the limited professional and career building pathways for CHWs contributing to lower wages, lack of career advancement, turnover, attrition, and workforce instability. Study findings stressed the importance of retaining skilled and experienced CHWs and educating health professions about CHWs' critical roles, which will decrease attrition, enhance professional growth, and improve program quality. Findings also suggest that higher wages, valuing lived experience over formal education, and participation in additional training opportunities should constitute the primary factors considered for career advancement.

CHW program evaluation and methods

As more CHWs become integrated into public health and healthcare systems, assessing the continuous impact CHWs have on population health management outcomes is important. These assessments are often criticized for lacking proper methodologies or participants' protection, especially those in more vulnerable populations. Killough et al. present a brief research report on CHW's unique perspectives of frontline CHWs who identified actionable barriers and facilitators that may impact representation of diverse groups in health research. As trusted members of the community, CHWs recognize their roles as facilitators in ensuring their community receive resources and benefit from being involved in research; as gatekeepers, CHWs take on the role of protectors so their community doesn't experience further trauma when engaging in research. Bush et al. present original research focused on the evaluation of a CHW-led self-management blood pressure (SMBP) program, which strove to improve hypertension management through raising awareness, education, navigation, advocacy, and resource assistance. Outcome measures indicate this CHW-led intervention improved management of hypertension through education on lifestyle changes (including creating lifelong healthy habits, coping skills, stress management, self-care, and accountability) impacting overall health and quality of life.

CHW certification

With any profession, validation of their competencies through some process of certification, licensure or registration is required. These requirements are more stringent for those working in healthcare settings. For the CHW workforce, more states have adopted or are examining CHW certification, which are often tied to requirements for billing, which in turn have direct implications on sustainability. Nielsen et al. share their lessons learned through an evaluation of the impact of the CHW certification in Massachusetts. Through a CHW survey pre-certification in 2016 and post- certification in 2021, they report on the 5-year efforts to a statewide CHW certification, as well as the impact. Their findings also revealed important gaps in the CHW research that are much needed to build a broader bank of knowledge in this area.

Conclusion

This Research Topic of eleven articles highlighted the following key areas needing further examination in order to continue to strengthen the community health worker practice. First, CHW programs, employers, and supervisors must acknowledge and commit to involving CHWs in all aspects of programs, leadership, and decision-making, aligning with "Nothing about us without us." Further research is needed on how to engage CHWs equitably. Second, the CHW practice has moved from acknowledging the essential role of CHWs to establishing and implementing a vision for CHW integration. The COVID-19 pandemic exposed many disparities and layers of population health management where CHWs can play impactful roles, especially in healthcare settings. Future studies can focus on actual integration practices of this vital workforce into complex systems and the impact value of CHW-integrated practices and CHW roles. Finally, funding support for CHW sustainability is still a major issue. More studies are needed on developing funding models to sustain the workforce. This Research Topic may not offer a complete picture but rather insights to building the CHW workforce and elements for strengthening the practice. We hope these articles shed new knowledge to inform and guide your practice. We also hope to build on efforts in these two issues that make up this Research Topic to lift up unheard community members, CHWs, and other voices in frontline practice settings to help us deepen our understanding of the field. We also expect to build on the tradition of CHWs playing roles as Peer Reviewers in future editorial endeavors to ensure authentic representation of voices—and most importantly, the accurate representation of CHW practice in published work about the CHW field.

Author contributions

LL: Conceptualization, Methodology, Writing—original draft, Writing—review and editing. JJ: Conceptualization,

Methodology, Writing—original draft, Writing—review and editing. DF: Conceptualization, Methodology, Writing—review and editing. ER: Conceptualization, Methodology, Writing—review and editing.

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Conflict of interest

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Community health workers: A sustainable health system innovation or just an emergency response?

Caroline Masquillier[1,2]* and Theo Cosaert[3]

[1]Department of Sociology, University of Antwerp, Antwerp, Belgium, [2]Department of Family Medicine and Population Health, University of Antwerp, Antwerp, Belgium, [3]Department of Public Health, Institute of Tropical Medicine, Antwerp, Belgium

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EDITED BY
Julie Ann St. John,
Texas Tech University Health Sciences Center, United States

REVIEWED BY
Noelle Wiggins,
Independent Researcher, Portland, United States
Ashley Wennerstrom,
Louisiana State University, United States

*CORRESPONDENCE
Caroline Masquillier
caroline.masquillier@uantwerpen.be

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Introduction

The detrimental effects of the COVID-19 pandemic on people's health and health systems worldwide are readily apparent (1). Even in well-resourced and well-performing health systems, this public health crisis has further exposed existing weaknesses—such as inequitable access to healthcare for socio-economically vulnerable groups, shortages of health personnel, and absence of rapid local interventions for prevention, health promotion and vaccination (1–3). The COVID-19 pandemic has made clear that health workers are needed on the ground to provide quick local responses (2, 3) and ensure access to care for all, including socio-economically vulnerable groups who are often left behind (4).

Early in the COVID-19 pandemic, community health workers (CHWs) became more widely recognized for their potential as an effective frontline response and capacity to improve access to care for populations living in socially vulnerable conditions (5). CHWs "are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables CHWs to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery" (6). As such, CHWs provide links to the healthcare system, deliver interventions at the individual and family levels, play a role at the community level regarding actions on social determinants of health and signal structural shortcomings in healthcare system to inform policy making (7–12). In countries with established CHW-programmes, CHWs were quick to respond to the pandemic at the local level to maintain community trust, provide clear and straightforward information, explain prevention measures and establish a contact tracing system (13).

COVID-19 pandemic as catalyst for innovation: Introduction of CHWs in Belgium

Whilst having detrimental effects for many populations living in socially vulnerable conditions (14), the COVID-19 pandemic also stimulated health system innovations (1). Inspired by CHW programmes in low-and-middle income countries (LMICs), researchers advocated for improved and expanded implementation of CHW programmes in high-income countries (HICs) (9, 15, 16). In the United States (US), for example, President Biden has called for the hiring of 100,000 additional CHWs as part of his strategy against the COVID-19 pandemic, building on the long-standing CHW initiatives in this country since their advent in the 1950s (5, 6). While CHW programs exist in some HICs – such as Canada (17), Australia (18), and New Zealand (19), among others—a scoping review concludes that CHWs in HICs "are an under-recognized, and therefore underutilized, public health workforce, which has a promising capacity to reduce health inequities in marginalized populations" ((17), p. e157).

Tapping into this potential, in response to the COVID-19 pandemic which exacerbated the access to care challenges for people living in socio-economic vulnerable circumstances, CHWs were introduced throughout Belgium at the start of 2021. More specifically, the Belgian Federal Government gave the National Institute for Sickness and Disability Insurance (NIHDI) and the National InterMutualist College (Intermut) the task to employ 50 CHWs in socio-economically vulnerable neighborhoods in ten Belgian cities. The CHWs followed a basic training and receive renumeration for their work. The CHWs' task is to improve accessibility to primary health care for people living in socially vulnerable conditions. The results of this first year are promising. A qualitative study shows that CHWs in the Belgian Federal project reach people who live at the intersection of different vulnerabilities, which are intertwined and can be mutually reinforcing. The CHWs consider the various barriers a person experiences when they provide them with support. The qualitative research concludes that CHWs can make an important contribution to improving access to care for people living in socially vulnerable circumstances, by tailoring their support to the needs of the target population and by signaling shortages in the healthcare system (20).

The Belgian CHW project emerged in a context without long-term funding or a sustainable policy vision on the issue (20). The budget was initially allocated for only one project year. It was renewed for a second year by the end of 2021. Experiences of CHW programmes in the past in other contexts allow us to learn what works today (2). We should not forget the disappointments of the programmes in the 1970s and 1980s in response to the Alma Ata Conference and the push for primary health care for all (10, 21). These taught us that CHW programmes are complex and a solid support system is needed to strengthen the CHW workforce through capacity building, systems readiness, CHWs' inclusion in all steps of the development and evaluation of CHW-projects and CHW credentialing opportunities, among others. In addition, to realize the full potential of CHWs, a long-term vision and sustainable funding is required (5, 22, 23). While functional CHW programmes are not cheap (22), they are proven to be cost-effective in reaching people living in socially vulnerable conditions (3). We should see CHW programmes not as a "temporary and underfunded afterthought," but as "an integral component of optimally functioning health systems" ((3), p. 14). Our study of the Belgian CHW project emphasizes this notion (20). To ensure that every person receives the health services they need, it is important that CHWs are linked to the broader health system (2). Setting up collaboration with actors in healthcare takes time, as well as planning and coordination (24). The qualitative results showed that in the Belgian Federal project, links between CHWs and the health system mostly emerged on an ad-hoc and individual basis. Lack of sustainable funding and a long-term vision among Belgian policy makers and funders inhibits integration and synchronization of the federal CHW programme with the Belgian health system (20).

Discussion

As we enter a new stage of this COVID-19 public health crisis, we need to seize the moment to build resilient health systems fit for the future (1). It is time to move beyond emergency response pilot projects in countries like Belgium. We should implement a CHW model that plays an integral role in the health system, following the example of countries like Brazil. Emerging as a pilot project amidst serious droughts in the 1980s, the Brazilian CHW programme is now one of the exemplary CHW models (2). In the Brazilian Family Health Strategy, primary care is provided by a Family health team—consisting of a physician, a nurse, a nurse assistant, and four to six full-time CHWs. Each team interacts with all households in a geographically defined community (25, 26). At least once a month, irrespective of need or demand, the CHW visits each household proactively in their micro-area. CHWs focus on all members of the household with a package of health-promotion activities that fully spans the life course (27). Other well integrated CHW programs into national public health care systems include those in Ethiopia, Bangladesh and Nepal, among others (10).

In a larger health system reform, CHWs fill a void in healthcare provision in a unique way by providing quick local responses and ensuring access to care for all (5). The launch of the Belgian CHW project demonstrated that there is political support for this innovative healthcare model. What we need now is to mobilize continued political will (2) to sustain the lessons learnt in times of crisis in times of plenty (16). It is time to endorse the future of CHWs and equitable and accessible healthcare for all, by looking beyond emergency responses, by strengthening this CHW workforce, by formulating a long-term vision and by ensuring sustainable funding for health system innovations set in motion by the COVID-19 pandemic.

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Community health worker insights on promoting research engagement with diverse populations

Cynthia M. Killough[1]*, Annemarie Madaras[2], Christina Phillips[2], Jennifer Hettema[3], Venice Ceballos[4], Jesus E. Fuentes[1], Heidi Rishel Brakey[1], Katherine Wagner[5] and Kimberly Page[5]

[1]Clinical and Translational Science Center, UNM Health Sciences Center, University of New Mexico, Albuquerque, NM, United States, [2]Department of Family and Community Medicine, UNM Health Sciences Center, University of New Mexico, Albuquerque, NM, United States, [3]LifeStance Health, Scottsdale, AZ, United States, [4]Community Health Worker Initiatives, UNM Health Sciences Center, University of New Mexico, Albuquerque, NM, United States, [5]Department of General Internal Medicine, UNM Health Sciences Center, University of New Mexico, Albuquerque, NM, United States

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EDITED BY
Victoria Team,
Faculty of Medicine, Nursing and Health Sciences, Monash University, Australia

REVIEWED BY
Ryan Logan,
California State University, Stanislaus, United States
Daniel Semakula,
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Carl Rush,
Community Resources LLC, United States
Tabetha Brockman,
Mayo Clinic, United States
Nell Brownstein,
Centers for Disease Control and Prevention (CDC), United States

*CORRESPONDENCE
Cynthia M. Killough
✉ ckillo@salud.unm.edu

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Representation of diverse populations in health research enhances our ability to understand the factors that impact health, generalize results, implement findings, and promote social justice. The primary objective of the study was to understand the unique perspectives of frontline community health workers (CHWs) to identify actionable barriers and facilitators that may impact representation of diverse groups in health research. Focus groups with CHWs were conducted followed by thematic analysis. Results revealed five main themes: barriers/risks to research participation, facilitation of research, CHW roles, recommendations, and transparency. A novel finding was that some CHWs see themselves as both facilitators and gatekeepers. As facilitators, CHWs ensure their patient populations receive resources and benefit from being involved in research; as gatekeepers CHWs feel that they protect patient populations from experiencing further trauma, especially when engaging in research. Recognizing that in many communities there is a high reliance and trust with CHWs, can promote genuine and informed participation at all stages of research.

KEYWORDS

underserved and unserved populations, community health worker (CHW), barriers to research, underrepresentation, racial minorities, ethnic minorites

Introduction

In the U.S. significant health disparities may be explained, in part, by inadequate representation of diverse racial/ethnic and other sociocultural groups in clinical research (1). Disparities in clinical research compounds other social determinants of health and widens the gap in receipt of quality health services. Representation of diverse populations in clinical and translational research enhances researchers' ability to understand the factors that impact health, generalize results, implement findings and promote social justice. Underrepresentation is also a matter of health equity in that the lack of diverse populations in clinical trials and health research reduces opportunities to finding issues that are pertinent to these groups thus reducing treatment options as well (2, 3).

Federally, efforts to include underrepresented populations were supported by the National Institutes of Health (NIH) Revitalization Act of 1993, where the NIH was directed to establish guidelines for inclusion of women and minorities in clinical research (4). Despite these mandates and the demonstrated benefits of including ethnically diverse and medically underserved populations in research, inclusion remains a struggle (5), prompting investigation into factors that might impact representation.

For racial/ethnic minority participants, there are many barriers to research participation, including logistical concerns such as childcare, schedule conflicts, lack of transportation, language barriers, and stigma of research (6). Patients who are underinsured or uninsured may have a significantly harder time participating in clinical trials requiring costs of care (7). Additionally, the U.S.' history of the exploitation of minorities and marginalized communities for research has led to mistrust, fear, and eroded confidence in not only research and researchers but also includes hospitals, institutions, medical advances, medical professions and many more (8). A widely cited example of this occurred when Havasupai Tribe members consented to give blood as part of a diabetes research study, but later learned the samples had been used for other sensitive genetic studies without their knowledge or consent (9). Another example includes the now infamous Tuskegee Syphillis Study with socially and economically marginalized Black men (8).

The inclusion of representative community members, such as Community Health Workers, in the research process, may provide a solution to address barriers to research participation. Community health workers (CHWs) are members of larger healthcare teams who provide direct services such as screening, education, and counseling, as well as supporting delivery of and promoting access to other services. CHWs go by many different titles and in New Mexico are often referred to as Promotores/Promotoras de Salud (or Promotor/a) (10) and Community Health Representatives (CHRs) (11). According to the World Health Organization, CHWs are individuals who "should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities…(12)." As extensions of communities, CHWs may be advantaged to play important roles in the research process and their involvement may facilitate increased representation.

As members of communities served by health systems, CHWs are uniquely positioned to build trust and serve as liaisons between underrepresented community members and researchers. A review of the literature shows CHWs have played important roles in many health research projects already: CHWs have assisted in research focused on the planning, assessment, and implementation of hypertension and diabetes prevention interventions (13, 14), the delivery of child health services in rural communities (15), and the translation of research to practice in several contexts (16).

New Mexico is a geographically vast state, primarily composed of rural areas (17), the majority of people are Hispanic or Native American (18), and rates of poverty and other social determinants of health are high (19). In the current study, our investigative team conducted focus groups with a large cohort of CHWs in New Mexico to gather insights on practical strategies for promoting the inclusion of representative participants in research. In addition, CHWs are commonly found members of health teams in the state. These aspects make our state an ideal setting in which to explore factors affecting underrepresentation of diverse populations in health research. Furthermore, while inclusion of CHWs in the research process has been implemented with demonstrated success in practice, we may also be able to leverage the unique insights of this group by understanding their perspectives on research strategies that enhance or inhibit our ability to engage diverse groups in research.

Methods

The protocol for this study was reviewed and approved by the Institutional Review Board (IRB) of the University of New Mexico (UNM) Health Sciences Center (HSC) Human Research Protections Office (#19-606).

From the inception of this study our CHW expert author (VC) has been involved and consulted for best practices and guidance- even in consideration if this study should be pursued and if it would be of interest to CHWs. Through connections and previous collaboration efforts on projects, we reached out to the Director of the Pathways to a Healthy Bernalillo County (20) (referred to as Pathways hereafter) to strategize how best to recruit CHWs from all areas in the city. Pathways "…uses a version of the Pathways Model to identify vulnerable, underserved residents and connect them to health and social services. Clients are identified through interagency referral among the program's network of 13 community-based organizations. Community health [workers] help clients access additional health and social services, assist with coordination of care, and monitor client progress" (20). The Pathways Director invited researchers to come to a Pathways meeting to promote this research study. CHWs working with various organizations (including the UNM HSC as well as other community organizations, clinics, and agencies throughout Albuquerque) regularly attend, and this opportunity provided researchers an optimal chance to a diverse group of CHWs for the study. The Pathways Director noted that many if not all of the CHWs had previous experience with research through various projects.

TABLE 1 Community health worker demographic information.

	$n = 33$
Gender	
Female	25 (76%)
Male	8 (24%)
Age	
18–24 years	2 (6%)
25–34 years	6 (18%)
35–44 years	12 (36%)
45–54 years	8 (24%)
55–64 years	5 (15%)
Ethnicity (select all that apply)	
White	3 (9%)
Hispanic white	6 (18%)
Hispanic non-white	4 (12%)
Latino	8 (24%)
Native American	2 (6%)
Alaskan native	0
Native Hawaiian	0
Pacific Islander	2 (6%)
African American	3 (9%)
Asian	5 (9%)
Other	4 (12%)
Certified community health worker? ($n = 32$)	
Yes	11 (33%)
No	14 (42%)
Working toward becoming certified	7 (21%)
Work setting (select all that apply)	
Hospital	3 (9%)
Clinic (not hospital setting)	9 (27%)
Social service organizations	18 (54%)
Academic setting	0
Community mental health center	4 (12%)
Primary care	1 (3)
Correctional facilities	0
Homeless shelter(s)	6 (18%)
City/County department(s)	1 (3%)
Public school	2 (6%)

The study took place in January of 2020 in a community facility. Before the focus groups began we distributed a written IRB-approved information sheet, provided a verbal overview of the study, and also distributed an anonymous survey with basic demographic information. Forty-two CHWs were invited to participate in the study, and all (42) accepted. Participants were divided into five ($N = 5$) focus groups, with 8 CHWs in 3 groups, and 9 CHWs in the other two groups. The groups were well spaced out within a very large conference room with a trained facilitator at each group. One focus group was conducted in Spanish by a fluent facilitator and participants self-selected into that group. We designed a semi-structured focus group guide to gain actionable perspectives to help researchers increase representation of underserved communities in their projects. Prompted by the interview guide, facilitators also allowed the CHWs to lead the focus group conversations in the direction they wanted with the understanding that health research was the focus. Following are the primary questions from the guide that were asked of each group:

- What do you think about when you hear the word “research”?
- What stigma is associated with research in your communities?
- If you were part of a research study, what would you expect from the researchers during and after the study is over?
- What strategies should researchers use and avoid when approaching clinics, providers, or patients about research?
- What strategies should researchers avoid when approaching clinics, providers, or patients about research implementation/dissemination?

Each group discussion was audio recorded and transcribed verbatim. Each participant received a $40 merchandise card.

Analysis strategies

Transcripts of the audio recordings, including English and Spanish, were done by a professional transcription company. The coding team (CK, AM, CP, JH, and JF) analyzed transcripts using Consensual Qualitative Research techniques (21) and Vaismoradi et al.’s (22) stages to thematic development in qualitative content coders reviewed transcripts individually, came together to identify broad themes and underlying subthemes, assigned participant quotes to those subthemes, and finalized the themes. Two Spanish-fluent analysts (CK and JF), analyzed the Spanish speaking transcript, translated them back into English and then integrated those participant quotes into the larger analysis.

Results

All 42 participants were asked to complete a short anonymous survey including demographics, gender, age, race/ethnicity, and work setting. Responses were submitted by 33 (79%) of the participants at the end of the focus groups. Of these 33, 76% were female, 36% were between the ages of 35–44 years, 24% identified as Latina/o, 42% were not certified CHWs, and 54% reported working in social services organizations (see Table 1).

Excel was used for the coding and thematic analysis. Five broad themes were identified by the coding team: (1) *Barriers/Risks* that may deter individuals from participating in research or deter CHWs from promoting research participation, (2) *Facilitation of research* such as factors to increase participation in research or encourage CHWs to facilitate research involvement, (3) *CHW roles* and the ways those roles impact decision making about research and their impact on research participation, (4) *Transparency* that CHWs requested of researchers and a desire that any and all information about the research project be provided up front, and (5) *Recommendations* or concrete tips, advice, and strategies CHWs recommended for researchers seeking to work with their populations (see Table 2). Below, we provide a description of each identified theme.

Theme 1: Barriers/Risks

We coded participant statements as *Barriers/Risks* if CHWs identified challenges to research participation. Three subthemes emerged: special populations barriers/risks, nothing is done with the results, and research is not for minorities.

Subtheme 1: Special populations barriers/risks. CHWs discussed barriers or risks that specific special populations, such as underserved or underrepresented populations, face in order to participate in research. One CHW mentioned "If the research is going to get the name [of the participant] and the nationality or immigrant status… some people with problems with immigration don't want to provide any [identifying information]." Another CHW also brought up concerns regarding legal risks of research participation, "I think with the current administration [2016–2020], there's a lot of people because of their immigration, they are scared to come out to participate in any research because they are not sure what is the purpose of the research or that kind of things," and another CHW continued,

> "… We serve a lot of people that don't have a lot of resources… it's a pretty negative connotation especially when we're talking about immigrant communities with legal ramifications. Why am I going to involve myself in something that includes my information, my opinion, when I don't really know what's going to happen or I don't know if I'm going to be able to stay safe?"

Subtheme 2: Nothing is done with the results. An issue that CHWs brought up was that participants may not see the value in participating because they are not confident that results and the findings will positively impact or be given back to their community as one CHW pointed out: "Are you going to come back and give the report back to our community? Because if [community members are] participating, they want to know why. It's because sometimes they say, "Well, the community doesn't want to participate." Yes. We don't want to participate because you never come back and tell me the results." Another CHW added, "That's the other issue. We do research. We find the problem. And we give [researchers] ideas of solutions. But then nothing happens. And then the organizations are not held accountable."

Subtheme 3: Research is not for minorities. CHWs discussed perceptions that people of color do not think research is for them and that societal racism extends into research. "The stigma...is that Black people don't matter, so they feel like they don't need to do research on us because there's not that many of us in Albuquerque let alone the state of New Mexico. So, when they do research, they don't even include us in it." Another CHW added, "Well, we have the same situation… Latinos. Most of the research programs are for other kind of people but no Latinos, no African American, no different people."

Theme 2: Facilitation of research

CHWs indicated they perceive research as valuable and that it can improve patient care and outcomes, particularly when it directly informs the patient population they serve: "We can't just take up every research [project] that comes up...it has to be important." Another CHW stated, "You get to see what populations need more help, need more resources...so that we can try to fix that." In one case, a CHW highlighted that research actually was important in supporting the value of CHWs within clinics. CHWs also reported valuing monetary benefits that are paid directly to research participants as well as funds that might be provided to a clinic or program to support as part of research collaborations.

Theme 3: CHW roles

Two subthemes emerged under CHW Roles. First, CHWs discussed the importance of the community trust they hold, and the responsibility to be accountable to their patients, which extends to ensuring their patients are informed of research outcomes from the studies patients have participated in. For example, one person suggested, "...Whenever we're working with the researcher... there should be a date set... When are you going to come back and report back to the community? So we can let our community know, by this date...we're going to get the research back. We're going to get the report, whether it's good or whether it's bad." A second subtheme

TABLE 2 Codebook and quote examples from Community Health Worker (CHW) focus groups.

Theme	Description of theme	Exemplar quote
Barriers/risks	Any mention of barriers to research such as past experiences, quality improvement, special populations. considerations, stigma, etc.	
Subtheme 1. Special populations barrier/risks	CHWs describe barriers or risks that specific special populations, such as underserved or underrepresented populations, face in order to participate in research.	"If the research is going to get the name [of the participant] and the nationality or immigrant status… some people with problems with immigration don't want to provide any [identifying information]."
Subtheme 2. Nothing is done with the results	CHWs describe any barriers or challenges to research due to the uncertainty the result will have a positive impact or given back to their community.	"Are you going to come back and give the report back to our community? Because if [community members are] participating, they want to know why. It's because sometimes they say, 'Well, the community doesn't want to participate.' Yes. We don't want to participate because you never come back and tell me the results."
Subtheme 3. Research is not for minorities	CHWs describe perceptions that people of color do not think research is for them and that societal racism extends into research.	"The stigma...is that Black people don't matter, so they feel like they don't need to do research on us because there's not that many of us in Albuquerque let alone the state of New Mexico. So, when they do research, they don't even include us in it."
Facilitation of research	CHWs describe how they perceive research as valuable particularly when it directly informs the patient population they serve.	"You get to see what populations need more help, need more resources...so that we can try to fix that."
Community Health Worker Roles	The roles that CHWs fulfill within their patient/client interactions and meanings they attach to them.	
Subtheme 1. Accountable to patients	Any mention of the CHWs expressing that they are ensuring their patients are informed of research outcomes from the studies patients have participated in.	"...Whenever we're working with the researcher... there should be a date set... When are you going to come back and report back to the community? So we can let our community know, by this date...we're going to get the research back. We're going to get the report, whether it's good or whether it's bad."
Subtheme 2. Gatekeepers	CHWs describe how they must weigh the risks and benefits of their patients' participation in research studies.	"They're somebody you've been seeing for a while. You do care about them. You want to know that there is nothing bad going to happen. I mean, that they are safe if they are going to be answering or doing whatever it is...through your research. That they're going to be safe."
Transparency	References made to researchers needing to be up front and clear in all aspects of the research process.	"Pienso que deben clarificar bien el concepto de lo que quieren ustedes investigar y aclarárselo bien a la comunidad, a nivel, porque no es por la falta de educación ni nada. Entonces, no conocen nada sobre lo que es… una investigación." (I think that you should clarify well the concept of what you want to investigate and clarify it well to the community, at the level, because it is not due to the lack of education or anything. So, they don't know anything about what an investigation… is.)
Recommendations	CHWs discuss recommendations for researchers to approach and engage with their populations.	
Subtheme 1: Remuneration or resource transaction	CHWs describe ways researchers can think of ways, monetarily or by providing other resources, to pay their populations for their time and contributions.	"We usually have to have a snack or a daily bus pass for them to even consider going to a focus group or something. So that would be something... we would have to think of ahead of time or else they're not going to participate."
Subtheme 2: Ensure a physical presence	Any mention to researchers needing to approach and engage with patient populations in-person.	"Showing up a couple days [in advance] that way we get familiar with your face… It's such an interpersonal job anyway. The position of an aggregator or CHW, you become part of a family unit with your clinics and the clinical staff or whoever else you're working with… we get wrapped into the whole tapestry. It's personal."
Subtheme 3: Work within the existing system	Any mention to researchers looking into systems in place surrounding their populations and the professional hierarchies established within organizations or agencies in order to overcome barriers to research.	"Contact a leader in the community and then the leader explains to the community because...if they respect someone in the community, they're going to hear everything [about the research] and participate."
Subtheme 4: Words matter	Any mention of researchers needing to be aware of the language they use and avoiding certain words or phrases around CHW's patient populations.	"Avoid words like alien, illegal. Even when we're talking about substance use, I think saying substance abuse, drug abuse, has a certain connotation and when you're talking to users."

was that some CHWs see themselves as gatekeepers between researchers and the community they serve, and they must weigh the risks and benefits of their patients' participation in studies. CHWs expressed the imperative priority of protecting vulnerable patient groups from experiencing unforeseen risks of research participation, such as those who have histories with trauma, or who are undocumented: "They're somebody you've been seeing for a while. You do care about them. You want to know that there is nothing bad going to happen. I mean, that they are safe if they are going to be answering or doing whatever it is...through your research. That they're going to be safe."

Theme 4: Transparency

"Transparency" emerged as the need for researchers to be up front and clear in all aspects of the research process and to be able to communicate these pieces effectively to participants. One Spanish speaking CHW said,

> "Pienso que deben clarificar bien el concepto de lo que quieren ustedes investigar y aclarárselo bien a la comunidad, a nivel, porque no es por la falta de educación ni nada. Entonces, no conocen nada sobre lo que es… una investigación." (I think that you should clarify well the concept of what you want to investigate and clarify it well to the community, at the level, because it is not due to the lack of education or anything. So, they don't know anything about what an investigation… is.)

Another CHW followed up: "… Every research is important to get whatever it is that the research needs or money or funding, whatever it is. But I think it's just how you ask the questions, how you do the research. What is it for? So that the people can participate honestly on the research."

Theme 5: Recommendations

CHWs discussed several recommendations for researchers to approach and engage with their populations. There were four subthemes that emerged: remuneration or resource transaction, ensure a physical presence, work within the existing system, and words matter.

Subtheme 1: Remuneration or resource transaction. CHWs recommended researchers think of ways, monetarily or by providing other resources, to pay their populations for their time and contributions, monetarily or with other resources. One CHW noted, "We usually have to have a snack or a daily bus pass for them to even consider going to a focus group or something. So that would be something... we would have to think of ahead of time or else they're not going to participate." Another CHW added, "The patients are struggling with transportation and babysitting or things like that… what could you do to help them in order to help you?"

Subtheme 2: Ensure a physical presence. Another recommendation was researchers need to approach and engage with their populations in-person as one CHW discussed:

> "Showing up a couple days [in advance] that way we get familiar with your face…It's such an interpersonal job anyway. The position of an aggregator or CHW, you become part of a family unit with your clinics and the clinical staff or whoever else you're working with…we get wrapped into the whole tapestry. It's personal."

Another CHW recommended,

> "I think coming in with a physical brochure and… hand[ing] out the brochures, meeting with the supervisor.... And getting their thoughts on the approach and the clientele that they work with. And that way, when they do come for the study [patients] know... what to expect or what kind of reaction they may be getting. It prepares the researcher as well. Kind of doing homework."

Subtheme 3: Work within the existing system. CHWs recommended researchers look at the systems in place surrounding their populations and the professional hierarchies established within organizations or agencies for which they wish to engage. For example, one CHW recommended researchers could "Contact a leader in the community and then the leader explains to the community because...if they respect someone in the community, they're going to hear everything [about the research] and participate." Another CHW added,

> "Well, I think that you have to approach the director or whoever's in the top before us. After that... What is the research all about? And then go from there. I mean, we're at the end. We're at the communication between you guys, the research, and the family because we have the connections, because we work with the families, but it just depends on what the study is all about and then us, we try to do our best."

Subtheme 4: Words matter. The final recommendation that emerged was that the words researchers use when addressing participants, even when bringing up the topic of research, mattered. For example, CHWs recommended researchers, "Avoid words like alien, illegal. Even when we're talking about substance use, I think saying substance abuse, drug abuse, has a certain connotation and when you're talking to users." Another CHW agreed: "Alien, for example, it's written and it's the proper word because the politics. The government put it. But in reality, it's not so friendly because I'm not Hispanic. I'm not an alien." A third CHW said, "But you see also, the wording, if you go to a community that is burned out for so-called being the instrument of research, don't come and say, "I'm going to do a research." I would remove completely the *research* word."

While CHWs are often called upon to facilitate aspects of research as well as observe the research process within health settings and hear patient perspectives (23, 24), we interpreted the emerging themes to mean that some CHWs see themselves as both facilitators and gatekeepers to their patient populations. As facilitators, CHWs ensure their patient populations get the resources they need and benefit from being involved in research. As gatekeepers, CHWs feel they must protect patient populations from experiencing more trauma, including when engaging in research. Both of these roles were encompassed in a back-and-forth discussion by the CHWs, "...So being that we're all community health workers, shouldn't it be our responsibility, if we're really good at doing our job, to piggy-back off of the researchers and find out, "Hey, what's going on? What was done with that study?" and then we go back and relay it to the community?," to which their colleague responded "...I am accountable to the community... we're accountable to the community."

Conclusion

The primary objective of the current study was to understand the unique, frontline perspectives of CHWs and identify actionable barriers and facilitators that may impact representation of diverse groups in research. A novel dichotomy emerged in the way CHWs view their own roles that, to our knowledge, has not been previously published. Some CHWs see themselves as both facilitators and gatekeepers to their patient populations. CHWs are integral to bringing a viewpoint to their patients. Researchers may not be aware that for some communities CHWs represent a group with whom there is a large power imbalance. Recognizing that in many communities there is a high reliance and trust with CHWs, can promote genuine and informed participation at all stages of research. CHWs emphasized the need for researchers to be transparent from the beginning of the project and communicate all aspects of the research process in a way that is effective and understandable by all participants. Furthermore, CHWs reported they feel research is not for minorities or people of color because they are often only a fraction of the population at large (i.e., only 2.6% of NM is Black or African American) (25). This is alarming if the goal is to increase representation from racial/ethnically diverse groups in health research.

It is important to note that a few of the themes that emerged from the focus groups are in line with previous studies. Under the *Special population barriers/risks* subtheme, CHWs discussed participant's immigration status and the challenges facing these populations in research participation. Undocumented immigration status impedes many individuals from participating in many different facets of health research and healthcare which is a largely discussed prevailing issue among researchers and healthcare providers (26–28). The *Remuneration or resource transaction* subtheme is also documented in the literature; however, opinions on monetary compensation and context are still debated. Still, in accordance with the recommendations of the CHWs in our study, it is advised to consider compensation for research participation. Furthermore, the *Nothing is done with the results* subtheme aligned with our own goals of data dissemination and knowledge of best practices, and as this paper went into submission a date and time was set to disseminate the results of this study back to the CHWs at Pathways.

Considering these themes, there are significant opportunities to continue and expand this knowledge and promote research engagement with historically excluded diverse populations. First, working with CHWs from the inception of a study could not only inform the research itself but could also provide a unique opportunity to strategize ways in which participants and the community could benefit from the study (i.e., the study could be tied to a community education effort or helping to secure sustainable funding for CHWs). Next, when researchers request assistance from CHWs, it is worthwhile to consider the multifaceted nature of how CHWs view their roles and expertise. Also, less time is needed focusing on convincing CHWs the value of research and focus could instead be placed on collaboration to highlight how research can support their work efforts and their patients. In addition, from the start of the project, researchers could find ways to help CHWs better understand participant confidentiality and how their patient's contact information will be stored and used. Next, researchers could take time to show CHWs how their patients can benefit from research, what incentives and resources are available, and how they plan on disseminating findings once the project has ended. Finally, researchers could prioritize dissemination of their results back to communities in accessible and meaningful ways, using plain language. This is consistent with other research showing dissemination of findings encourages future participation in research and fosters trust between researchers and participants (24). In reference to Theme 1: Barriers/Risks and its subsequent subthemes it appears that a common conception about research among CHWs and their patient populations is that research does not leave anything of value for the participants and furthermore does not contribute to the community; arranging ways in which researchers could bring the data back to the participants and the community early in the study could help in changing these negative perceptions of research and researchers. We would also like to note that at the time of submitting this paper, we have been in contact with Pathways to set up a time where the results of this study can be disseminated back to CHWs with recommendations on how best to do so (i.e., power point presentation, infographic, etc.).

The current study also provided opportunities for reflexivity on the researcher's experiences and training and how this affected the way the data was collected and interpreted. Our research team worked in varying departments across our university campus, however we all fall under the community engagement umbrella in health research. Our team is made up of qualitative experts- some who have prior experience working directly with CHWs and others were new to the field. The qualitative method we used allowed us to view CHWs as experts and we followed their lead through the interview guide. While analyzing the data a strength of our team is the varying degree to which we had experience working with CHWs which allowed us to view the data more objectively as the team discussed various themes that emerged. We also acknowledged that however objective we tried to be, we were still not CHWs which is why we were grateful for the insight and assistance from our collaborative CHW expert coauthor (VC). We also understood that while one person is not representative of all CHW voices, their experience and expertise was still valued as a guide for our efforts.

Several limitations exist in the current study. We were unaware of the need for a focus group to be led by a Spanish speaking facilitator until we got to the CHW meeting. Fortunately, one of our researchers was fluent and could facilitate a group in Spanish but had to translate the questions in the moment. Additionally, the focus groups were held simultaneously in the same large open space, rather than separate, private spaces. As such, there was crosstalk and lack of privacy that may have prevented some participants from sharing more. We did have some missing data on participant demographics, as not all the participants returned the demographic survey, which did include instructions saying they were not obligated to finish or take the survey. The findings of the current study are also from CHWs who serve a majority Hispanic population. These factors (missing data and CHW population focus) may limit generalizability of our results. Finally, the COVID-19 pandemic began soon after the focus groups and disrupted workflow. During this time researchers were unable to meet as they adapted to stay-at-home orders and other remote work guidelines.

Moving forward there are various actions that can be done to assist both CHWs and researchers to increase patient research participation. For example, CHW certification programs could look into ways of incorporating research education into their curriculum. This is in line with recommendations from the CHW Core Consensus (C3) project which included *participating in research* within CHW's scope of practice (29). CHWs who understand research processes and research in general can better aid their patients who may be interested in research participation. As was made clear by the CHWs in the current study, the purpose of research is not always clear, meaning more information is needed on the front-end of projects before individuals decide to participate. Also, exposing CHWs to other research approaches (e.g., Rationale for Research Participation Framework) could bolster their knowledge about why participants choose to participate in health research, including risk-benefit and reciprocity perspectives (30). There is considerable room for improvement from researchers and institutions, considering some barriers to engaging diverse populations are well documented and restated in the current study. Finally, opportunities such as taking Community-Based Participatory Research training (31) may help researchers be more responsive to community needs and design their studies in a more community-based and community-friendly manner.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by University of New Mexico Health Sciences Center Human Research Protections Office (#19-606). Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

CK, AM, CP, JH, and JF contributed to the analysis and writing on the first draft and subsequent versions thereafter. VC, HR, and KW assisted with subsequent versions of the manuscript. KP consulted on the study itself and provided guidance and support throughout the writing process. All authors contributed to this paper and fulfill the authorship criteria and reviewed and approved the final draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Mohan Tanniru,
University of Arizona, United States

REVIEWED BY
Sarah Goff,
University of Massachusetts Amherst,
United States
Penrose Jackson,
Vermont Public Health Institute, United States

*CORRESPONDENCE
Victoria M. Nielsen
✉ victoria.nielsen@mass.gov

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Evaluating the impact of community health worker certification in Massachusetts: Design, methods, and anticipated results of the Massachusetts community health worker workforce survey

Victoria M. Nielsen[1]*, W. W. Sanouri Ursprung[1], Glory Song[1], Gail Hirsch[2], Theresa Mason[2], Claire Santarelli[3], Erica Guimaraes[4], Erica Marshall[5], Caitlin G. Allen[6], Pei-Pei Lei[7], Diane Brown[7] and Bittie Behl-Chadha[7]

[1]Massachusetts Department of Public Health, Office of Statistics and Evaluation, Bureau of Community Health and Prevention, Boston, MA, United States, [2]Massachusetts Department of Public Health, Office of Community Health Workers, Bureau of Community Health and Prevention, Boston, MA, United States, [3]Division of Health Protection and Promotion, Massachusetts Department of Public Health, Bureau of Community Health and Prevention, Boston, MA, United States, [4]Mass General Brigham, Boston, MA, United States, [5]Division of Community-Based Prevention and Care, Massachusetts Department of Public Health, Bureau of Community Health and Prevention, Boston, MA, United States, [6]Department of Public Health Sciences, College of Medicine, Medical University of South Carolina, Charleston, SC, United States, [7]Office of Survey Research, University of Massachusetts Chan Medical School, Shrewsbury, MA, United States

Background: Professional certification of community health workers (CHWs) is a debated topic. Although intended to promote CHWs, certification may have unintended impacts given the grassroots nature of the workforce. As such, both intended effects and unintended adverse effects should be carefully evaluated. However, there is a lack of published literature describing such effective evaluations with a robust methodology. In this methods paper, we describe a key component of evaluating CHW certification in Massachusetts-the Massachusetts CHW Workforce Survey.

Methods: Design of the surveys was informed by a program theory framework that delineated both positive and negative potential impacts of Massachusetts CHW certification on CHWs and CHW employers. Using this framework, we developed measures of interest and preliminary CHW and CHW employer surveys. To validate and refine the surveys, we conducted cognitive interviews with CHWs and CHW employers. We then finalized survey tools with input from state and national stakeholders, CHWs, and CHW employers. Our sample consisted of three frames based on where CHWs are most likely to be employed in Massachusetts: acute care hospitals, community-based organizations, and ambulatory care health centers, primarily community health centers and federally qualified health centers. We then undertook extensive outreach efforts to determine whether each organization employed CHWs and to obtain CHW and CHW employer contact information. Our statistical analysis of the data utilized inverse probability score weighting accounting for organizational, site, and individual response.

Anticipated results: Wave one of the survey was administered in 2016 prior to launch of Massachusetts CHW certification and wave two in 2021. We report descriptive statistics of the three sample frames and response rates of each survey for each wave. Further, we describe select anticipated results related to certification, including outcomes of the program theory framework.

Conclusions: The Massachusetts CHW Workforce Survey is the culmination of 5 years of effort to evaluate the impact of CHW certification in Massachusetts. Our comprehensive description of our methodology addresses an important gap in CHW research literature. The rigorous design, administration, and analysis of our surveys ensure our findings are robust, valid, and replicable, which can be leveraged by others evaluating the CHW workforce.

KEYWORDS

community health workers, surveys and questionnaires, certification, methods, healthcare reform

Introduction

A community health worker (CHW) is a public health worker who utilizes their unique understanding of the populations they serve to carry out several roles, such as health education, outreach, and care coordination (1). Known for shared personal experiences with the populations they serve and intimate knowledge of the communities in which they live and operate, CHWs are a critical asset in a multitude of public health activities. CHWs are known by a variety of job titles, an indication of the diverse populations with which they work and the broad range of services they provide, which often arise organically from community needs (1–3). The CHW's ability to establish trust and rapport, embedment in social networks, and thorough knowledge of the strength, resilience, and resources in the community are attributes that cannot be replicated in any other profession.

Although early research of the efficacy of CHWs was hindered by substantial methodological limitations and program implementation problems, a multitude of recent studies using robust methods has demonstrated the impact CHWs have on an array of measures and outcomes (4–7). For example, a systematic review of CHW-led interventions in populations with pediatric asthma suggests that such interventions can reduce symptoms, decrease activity limitations, and reduce emergency and urgent care use (6). Another systematic review of CHW interventions among adult populations with diabetes suggests that CHWs have significant impacts on physical health, knowledge of diabetes, self-care, and wellbeing (7). Although further research is needed, including more rigorous integration of theoretical frameworks into program design and evaluation, the literature increasingly demonstrates the role CHWs play in improving health outcomes of underserved populations (4, 6). Further, the passage of the Patient Protection and Affordable Care Act in 2010 not only increased healthcare's accountability for mitigating upstream factors that can be addressed by CHWs, but also facilitated CHW integration into healthcare teams and delivery models (8–12). Taken together, the legitimate role CHWs play in improving health in both community and healthcare settings has become apparent to a wider audience in the past two decades.

Given this wider recognition, professional certification of CHWs has been raised as a means to legitimize their role, produce a clearer definition of scope, and increase opportunities for sustainable financing and reimbursement (13, 14). However, there is no national certification of CHWs and states pursuing certification have taken heterogeneous approaches. In 2010, the Massachusetts legislature passed an Act Establishing a Board of Certification of Community Health Workers, which in part began the creation of a process of certifying Massachusetts CHWs (15). Over the next decade, CHWs, CHW employers, state officials, and advocates worked to implement an equitable, accessible certification process. In 2018, CHW certification by the experience pathway was launched, which is administered by the Massachusetts Department of Public Health (MDPH) Bureau of Health Professions Licensure (16). The combined training and work experience certification pathway launched in 2021 and at the time of this publication there are four board-approved core competency training and education programs (17).

Although certification is intended to champion and promote the CHW workforce, there may be unintentional adverse impacts (13, 18). One element that makes CHWs so effective is their similarity with the populations they serve, a characteristic that certification may alter (13). Shifts in the demographics of the CHW workforce, loss of job opportunities to CHWs who are not certified, inequitable increases in salary by demographics or certification status, and the cost and burden of obtaining certification are other notable concerns (13, 14, 18). Finally, certification must always be considered voluntary and should not be utilized as a requirement for employment or promotion. As such, CHW employers' certification-related perceptions and requirements should also be monitored.

Population surveys of CHWs and CHW employers are an important tool in evaluating the impact of certification; however there is a notable gap in the published literature describing such methods. Additionally, conducting population surveys presents several methodological challenges (19). Previously published surveys and evaluations of the impact of CHW certification frequently do not perform statistical adjustment of the data; rely on non-probability sampling; do not collect data on important confounders, such as type of organization in which the CHW is employed; or have limited generalizability due to an unclear definition of the CHWs included in the sample, especially given the variety of titles under which CHWs operate (20–26). Given the far-reaching implications such evaluations may have, it is essential that methodology be robust to ensure results are valid and generalizable. In this manuscript we describe our rigorous and replicable methodology in the design, administration, and statistical analysis of the Massachusetts CHW Workforce Survey, which is a key tool in evaluating the launch of Massachusetts CHW certification.

Materials and equipment

Institutional review board

Survey procedures were reviewed by the University of Massachusetts Chan Medical School (UMass Chan) institutional review board. The project was deemed non-human subjects research. Additionally, responses and contact information are considered confidential information and are maintained behind MDPH and UMass Chan Office of Survey Research firewalls on password protected computers. Any release of aggregate survey data must adhere to standards set by the MDPH Privacy and Data Compliance Office (PDCO).

Sample frame development

We began development of the survey sample by searching for a comprehensive list of all organizations in the state within each of the following core frames: acute care hospitals (hospital frame); community-based organizations (CBO frame); and Massachusetts community health centers (CHCs) and federally qualified health centers (FQHCs) (health center frame). These three core frames do not reflect an exhaustive list of settings in which CHWs are employed; rather, they reflect evaluation priorities in Massachusetts as well as findings from past surveys conducted in Massachusetts that indicate where CHWs are likely to be employed (22). Additional frames, such as mental health centers and outpatient pediatric clinics, were considered but could not be included due to resource limitations. However, because CHCs and FQHCs provide mental health and pediatric care, our survey likely did reach a sample of CHWs providing these services.

We created preliminary lists of organizations with contact information in each frame using publicly available sources: a full list of acute care hospitals and phone numbers was collated from the MDPH Bureau of Healthcare Safety and Quality, the state government entity responsible for licensing of all healthcare providers in the state; a list of CHCs and FQHCs were obtained from the Massachusetts League of Community Health Centers and Health Resources and Services Administration, respectively; and CBOs were obtained *via* existing state public health records, exhaustive internet search, historical knowledge of CBOs in Massachusetts from a network of key informants, and organization registries kept by the Massachusetts Association of Community Health Workers (MACHW) (20, 27). Unlike the former two sample frames, identification of CBOs was challenging as there is no comprehensive list of such organizations; nonetheless, we undertook extensive efforts to include as many CBOs as possible. Examples of CBOs included in our sample frame include organizations providing addiction recovery services; access to housing and food; faith-based organizations; and domestic violence services. We then undertook an exhaustive internet search to determine whether organizations in each frame operated at multiple sites in Massachusetts and to obtain publicly available contact information for each site.

The three core frames are comprised of the following: 43 hospitals in wave one and 42 in wave two, 56 health centers in wave one and 57 in wave two, and 158 CBOs in wave one and 171 in wave two. Unfortunately, expanding to additional frames in the same comprehensive and systematic fashion where CHWs are employed, such as additional community health clinics that are not CHCs or FQHCs, hospitals focusing on special populations, and state and local health departments, was not feasible given time and funding limitations. As such, we incorporated into each frame a small selection of additional organizations that serve similar functions as their assigned frame: urgent care, healthcare networks, pediatric hospitals, and veteran's hospitals in the hospital frame ($n = 7$ in wave one, $n = 8$ in wave two); community-based health clinics focusing on specialty services such as women's health and reproductive health in the health center frame ($n = 10$ in each wave); and divisions of health departments providing community-based services in the CBO frame ($n = 10$ in each wave). Although these are not comprehensive, we felt it was nonetheless important to include these additional organizations to reach as many CHWs as possible in Massachusetts.

Survey tool development

Survey tools were developed in collaboration with the MDPH Office of CHWs and Office of Statistics and Evaluation; the Board of Certification of CHWs; MACHW; and the UMass Chan Office of Survey Research. Design of the surveys was guided by our development of a program theory framework that broadly endeavored to capture how launch of Massachusetts CHW certification could both positively and negatively impact the Massachusetts CHW workforce. This framework was developed from two sources. First, we conducted an extensive review of the literature, including peer reviewed articles, gray literature, and reports, that identified gaps in CHW certification research and evaluation, perceptions and concerns regarding CHW certification, previous surveys of the CHW workforce and CHW employers, and findings from other states that had launched CHW certification. The second source was extensive engagement with state and national veteran CHW subject matter experts (SME). This includes experts with decades of expertise in CHW-related research (GH, TM); perspectives gathered from engaging with CHWs and CHW employers across Massachusetts; and input from local, state, and national partners. These efforts resulted in the derivation of several key evaluation questions. However, due to resource limitations, five of these were prioritized to assess the impact of CHW certification in Massachusetts. Using these evaluation questions as a guide and leveraging the expertise of researchers with decades of experience in survey research, design, psychometrics, and administration (WWSU, CA, TM, BBC, PPL, DB), we developed measures and corresponding CHW and CHW employer survey questions.

Supplement A contains a matrix of these evaluation questions, measures, and corresponding CHW and CHW survey questions. We aligned select questions on the CHW and CHW employer surveys to enable contrasts between CHW employer and CHW perspectives, which are aligned in the table text. With these measures defined, we then designed activities that would promote Massachusetts

CHW certification as well as support all CHWs in Massachusetts regardless of decision to seek certification, such as: increasing awareness of the Massachusetts CHW Board of Certification; sharing training opportunities offering continuing education unit (CEU) credits with CHWs; establishing core competency training programs and centers by the Massachusetts CHW Board of Certification; and providing targeted technical assistance to CHWs and CHW employers. Examples of technical assistance include processes to integrate CHWs into clinical care teams and how to advocate for CHW access to and documentation of their work in the electronic health record.

Survey tool refinement and validation

Once we developed the preliminary CHW and CHW employer surveys, the UMass Chan Office of Survey Research conducted cognitive interviews with 10 CHWs and 10 CHW employers during which they reviewed survey questions and responses as well as obtained additional information to inform survey design. Interview participants spanned the three organization types and each interview was ∼45–50 min in length. Verbal consent was obtained, and participants were notified that they could discontinue at any time.

In addition to reviewing the survey tools, the cognitive interviews gathered additional information regarding employment attributes, funding sources, roles and activities, integration into care teams, perceived value of CHW work within the organization, training, and perceived benefits and barriers related to certification. See Supplements B, C for the CHW and CHW employer interview guides, respectively. The cognitive interviews served four purposes: provided feedback on the CHW and CHW employer surveys; informed the critical topics to be included in the survey to keep survey length reasonable; assisted in the wording of the questions and response options in a way that would validly resonate with the respondents; and guided in the design of specific response options to be included with each question.

After integrating the findings of the cognitive interviews into the surveys, we conducted additional cognitive interviews with state and national CHW SMEs to further refine the clarity, appropriateness, and comprehensiveness of survey questions. Additionally, MACHW and CHW Core Consensus Project (C3) reviewed each tool in its entirety and provided feedback. Finally, the CHW survey tool and the CHW employer survey tool were reviewed by a small group of CHWs and CHW employers, several of whom brought both the CHW and CHW employer perspective. The tools were further modified based on this feedback. Although formal testing is ideal in survey development, resource limitations and funding restrictions were a challenge in conducting additional validation. However, leveraging the subject matter expertise of those developing and reviewing the survey, integration of findings from the cognitive interviews, and the tools undergoing review by several members of the target population enhanced the validity and reliability of the surveys.

As a result of these efforts, we finalized the survey tools that broadly covered the following domains: (1) Aspects of CHW employment, such as job title, pay, full or part-time employment, and organization information; (2) Role of the CHW within the organization, such as health issues addressed, health promotion activities, linkages to community resources, and work with special populations; (3) Trainings and certification of the CHW, such as receipt of the 80-h core competency training and trainings in specific disease areas; (4) Clinical care team integration, including use of electronic health records and interactions with the care team (asked of clinical organizations only); and (5) Certification, such as certification status, perceptions of certification, and ease of certification process. In the 2016 wave, the CHW survey tool was available in English only. In the 2021 wave, the CHW survey tool was translated into Spanish and Portuguese, given that these are the second and third most commonly spoken languages in Massachusetts and were the most frequently reported second languages on wave one of the CHW survey (28). Translation of the survey was intended to accommodate CHWs who were more comfortable communicating in a non-English language. The translated Spanish and Portuguese surveys were reviewed by a native Spanish and a native Portuguese speaker, respectively, to ensure accuracy and appropriateness of translations.

The English CHW employer and CHW survey tools can be found in Supplements D, E, respectively. In the attached supplements, questions that align between the CHW and CHW employer surveys are indicated in brackets (blue font) on the CHW survey tool. We then built the survey tools into the online survey platform Confirmit.

Methods

Obtaining contact information and survey administration

After collecting publicly available contact information for all organizations and sites within the sample frames, we initiated outreach prior to each wave of the survey launch to ascertain whether the organization and affiliated sites employed CHWs and to obtain the email addresses of CHW employers and CHWs working at the organization. MDPH and UMass Chan interviewing staff contacted each organization in the sample frame using a call script. Given the variety of roles and job titles CHWs have, interviewers used a fact sheet that provided detailed information on the roles, job titles, and responsibilities of CHWs (Supplement F). If during this initial outreach the contact expressed hesitancy to provide this information, interviewers offered to email an official letter from MDPH to establish the legitimacy of the survey. Regarding the hospital frame, determining which specific department in which a CHW worked within a hospital was notably challenging. As such, while collecting contact information we made the decision to obtain information on all CHWs from the general contact number from the hospital even if we could not identify the specific department that those CHWs were affiliated with. Organizations and sites not employing CHWs were indicated as such and were deemed not eligible for the survey. Please see Table 1 for organizational characteristics of CHWs and CHW employers who provided contact information.

There were several important lessons learned during this process. Using fact sheets and definition of CHWs was critical since most contacts did not know what a CHW was. Receptionists at the organization's general number often were unable to provide any information; as such, interviewers found it best to ask for managers responsible for hiring and payroll. Finally, contacting human resources departments, especially in large organizations, often did not prove fruitful. Overall, interviewers found it was best to be

TABLE 1 Organizational characteristics of CHWs and CHW employers included in the sample frame.

Organizational characteristics of the sample frame	Wave 1				Wave 2			
	Employers		CHWs		Employers		CHWs	
	*n**	%*	*n**	%*	*n**	%*	*n**	%*
	298		871		283		948	
Organization type								
Hospitals	84	28.1	173	19.8	44	15.5	108	11.3
Health centers	88	29.5	254	29.1	109	38.5	336	35.4
Community-based organizations	126	42.2	444	50.9	130	45.9	504	53.1
Organization size (based on number of employees)								
Small (1–49)	53	17.7	120	13.7	42	14.8	182	19.1
Medium (50–500)	132	44.2	478	54.8	93	32.8	376	39.6
Large (501+)	113	37.9	273	31.3	148	52.2	390	41.1
Neighborhood Stress Score (NSS) deciles**								
1–4 (−1.714 to −0.681)	20	6.7	106	12.1	19	6.7	62	6.5
5–7 (−0.680 to −0.228)	24	8.0	47	5.3	18	6.3	47	4.9
8 (−0.227 to 0.180)	35	11.7	92	10.5	41	14.4	156	16.4
9 (0.181 to 1.024)	56	18.7	106	12.1	50	17.6	155	16.3
10 (1.025 to 4.841)	163	54.6	520	59.7	155	54.7	528	55.6

*Column totals may not sum due to truncation and/ or missing values.

**NSS decile ranges based on NSS values for the state of Massachusetts. Select deciles were collapsed due to small cell size to protect confidentiality in adherence with the Massachusetts Department of Public Health Privacy and Data Compliance Office confidentiality procedures.

TABLE 2 Organizational characteristics of CHWs and CHW employers responding to the survey.

Organizational characteristics of survey respondents	Wave 1				Wave 2			
	Employers		CHWs		Employers		CHWs	
	*n**	%*	*n**	%*	*n**	%*	*n**	%*
	187		531		172		486	
Organization type								
Hospitals	48	25.6	108	20.3	33	19.1	70	14.4
Health centers	59	31.5	191	35.9	60	34.8	178	36.6
Community-based organizations	80	42.7	232	43.6	79	45.9	238	48.9
Organization size (based on number of employees)								
Small (1–49)	34	18.1	88	16.5	24	13.9	94	19.3
Medium (50–500)	79	42.2	259	48.7	60	34.8	200	41.1
Large (501+)	74	39.5	184	34.6	88	51.1	192	39.5
Neighborhood Stress Score (NSS) deciles**								
1–4 (−1.714 to −0.681)	12	6.4	41	7.7	13	7.5	31	6.3
5–7 (−0.680 to −0.228)	18	9.6	35	6.5	14	8.1	29	5.9
8 (−0.227 to 0.180)	26	13.9	63	11.8	27	15.6	86	17.6
9 (0.181 to 1.024)	36	19.2	64	12.0	33	19.1	80	16.4
10 (1.025 to 4.841)	95	50.8	328	61.7	85	49.4	260	53.4

*Column totals may not sum due to truncation and/ or missing values.

**NSS decile ranges based on NSS values for the state of Massachusetts. Select deciles were collapsed due to small cell size to protect confidentiality in adherence with the Massachusetts Department of Public Health Privacy and Data Compliance Office confidentiality procedures.

flexible and patient, and to talk to anyone who could provide any information. Often it took multiple efforts to obtain CHW and CHW employer contact information at a given organization.

One day prior to launch of the survey, the MDPH Office of CHWs sent an official prenotification email to all CHW employers and CHWs in the sample frame notifying them of the upcoming survey. This step was intended to reinforce legitimacy of the survey and improve response rates when organizations were later contacted directly. Attached to the email was an official letter from the MDPH Office of CHWs. The survey was then administered *via* email with a link to the survey. Wave one was administered between June 14 to August 1, 2016, and wave two between April 13 to July 1, 2021.

Statistical analysis

Once survey administration was complete, we reviewed data files for completeness, missingness, and duplication. After completion of this step, we used inverse probability score weighting (IPW) to account for non-response and permit valid population-level comparisons across survey waves. Regardless of the evaluation or research question assessed with these data (including evaluating the impact of CHW certification), IPW is a critical step in addressing bias introduced by non-response and differential response within and between waves of the survey. We generated inverse probability weights using propensity score models with PROC LOGISTIC in SAS 9.4 using a logit link function and Fisher's Scoring method (29). We ran three separate propensity score models to generate three separate sets of weights to account for response probability at different levels: organizational probability of response to initial outreach regarding organizational employment of CHWs, which included both eligible and ineligible organizations (ineligible meaning that the organization indicated that it did not employ CHWs); site probability of response to initial outreach regarding site employment of CHWs, which included both eligible and ineligible *sites* (*organizations* that confirmed that they did not employ CHWs as a whole were removed from this step); and individual CHW and CHW employer probability of response to the survey.

All three propensity score models included as predictors organization type (CBO, hospital, health center) and organization size. We determined organization size based on publicly available tax documents from ProPublica, from which we obtained the number of staff employed by the organization, excluding volunteers (30). We determined that this was a feasible approach given that the majority of the organizations in our sample frame were non-profit or not-for-profit. For the 2016 survey wave, 2015 tax filings were used and for the 2021 survey wave, 2020 tax filings were used. If tax filings were not available, filings were incomplete, or the organization was for-profit, we conducted an internet search on the organization's website to obtain these data. Employee size was categorized as small (<50 employees), medium (50–500 employees), and large (more than 500 employees).

In addition to organization type and size, the models for the site level and CHW and CHW employer level propensity scores included a Neighborhood Stress Score (NSS) variable developed by Ash et al. (31). This composite measure is derived from the American Community Survey (ACS) data of census block group estimates of poverty, education, access to transportation, and employment. A higher score indicates higher levels of neighborhood stress. We mapped NSS scores at the site level given that many organizations operate at multiple locations, which will likely vary in community characteristics. We categorized NSS into deciles, the ranges for which were determined using statewide NSS. We included NSS as a discrete variable in the models. Our inclusion of organization size, type, and NSS in the IPW endeavored to capture both organizational and community characteristics that we hypothesized to be associated with probability of response. The weights generated by each of the three stages were then multiplied together, resulting in a single weight for each respondent to the CHW and CHW employer surveys.

Anticipated results

In wave one, the response rate was 67% for the employer survey and 63% for the CHW survey. In wave two, the response rate was 62% for the employer survey and 53% for the CHW survey. Organizational characteristics of CHW and CHW employers responding to the survey are included in Table 2. CHWs responding to each wave of our survey are primarily female, most have some college education or higher, and the majority work full time. The representation of Black or African American CHWs declined between wave one and wave two, with the reduction distributed across White and Hispanic CHWs. In wave two, 26% of CHW employers reported employing certified CHWs and 15.6% of CHWs reported being certified by the Massachusetts Board of Certification. Please see Table 3 for characteristics of CHWs by survey wave.

Key findings will focus on the evaluation questions related to impact of certification, outlined in Supplement A. Additionally, strata will include CHWs vs. CHW employers; wave one vs. wave two; certified CHWs vs. non-certified CHWs; CHW employers reporting requiring certification for hiring vs. those reporting not requiring certification for hiring; and CHW employers reporting employing certified CHWs vs. CHW employers reporting that they do not. Note that the last three strata are available in wave two only, as Massachusetts certification launched after wave one was administered. Finally, findings may be stratified by additional variables to mitigate confounding, such as stratifying by employer characteristics.

An exhaustive list of anticipated results is beyond the scope of this paper. Examples of anticipated findings include whether employers are leveraging stable funding sources for CHW positions; if there are shifts in the perceived value of CHWs and CHW certification; whether there are changes in trainings and promotion opportunities available to CHWs; and whether CHWs have become better integrated into care teams. Additionally, we will assess awareness of Massachusetts CHW certification and ease of and attitudes toward obtaining certification in Massachusetts. Finally, we will further analyze shifts in the CHW workforce between survey wave one and wave two. CHW demographics we will analyze include gender, educational attainment, number of years working as a CHW, income, age, race, and ethnicity. However, if any changes are detected, they are likely multifactorial and not necessarily the result of launch of certification, such as natural variation in the workforce and impacts of the Coronavirus Disease-19 (COVID-19) pandemic. Differentiating these factors will become more feasible with additional administrations of the surveys.

TABLE 3 Characteristics of CHW respondents by survey wave.

Demographics of responding CHWs	Wave 1 (2016, $n = 531$)	Wave 2 (2021, $n = 486$)
	%*	%*
Employment**		
Full time, paid (at least 30 h per week)	90.0	85.8
Part time, paid (<30 h per week)	10.0	13.7
Is certified***	NA	15.6
Age (years)		
18–34	39.7	26.5
35–44	23.4	26.6
45 or older	36.9	46.9
Total years working as a CHW		
Up to 2 years	39.7	31.1
3–10 years	38.2	43.5
11 or more years	22.1	25.3
Gender**		
Female	80.8	78.5
Male	19.1	18.6
Education		
Up to some college or 2-year degree	40.3	40.5
4-year college graduate	37.5	34.6
More than 4-year college degree	22.2	24.9
Race/ethnicity		
Asian (non-Hispanic)	5.0	5.1
Black or African American (non-Hispanic)	19.7	13.3
Hispanic	28.1	31.9
Other (non-Hispanic)	4.9	6.2
White (non-Hispanic)	42.3	43.5
Languages fluent enough to communicate with individuals they serve****		
Spanish	31.4	34.2
Portuguese	8.4	7.3
Haitian Creole	4.4	4.3

*Column totals may not sum due to truncation and/ or missing values. Percentages in this chart reflect weighted survey data and are variably based on the total number of CHWs who responded to the question.

**Select response options (e.g., transgender, volunteer unpaid) were collapsed due to small cell size to protect confidentiality in adherence with the Massachusetts Department of Public Health Privacy and Data Compliance Office confidentiality procedures.

***Not applicable in wave one as Massachusetts had not launched certification.

****Top three languages, excluding English.

Discussion

Using a rigorous, systematic, and replicable approach, the Massachusetts CHW Workforce Survey serves as a critical tool to monitor the impact of CHW certification in Massachusetts and describe a large, growing, and diverse workforce. In conjunction with ongoing outreach and evaluation efforts conducted by the MDPH Office of CHWs and their partners, findings from these surveys will be critical in assessing impacts of certification in Massachusetts. The rigorous and methodological documentation of our survey methods increases feasibility of administering additional waves of the survey to monitor change over time and replicability of findings. Additionally, researchers, governments, and CHW advocates looking to administer their own surveys can utilize our tools and approaches to inform their work in conjunction with tools and resources currently available through the National Association of Community Health workers (NACHW), the Centers for Disease Control and Prevention, and other organizations (14, 32). Given the gap in the literature describing rigorous evaluations of CHW certification, it is not surprising that over the 6 years since we designed and launched the surveys we received numerous requests regarding best practices in evaluating CHW certification-including our survey tools and methods-from local, national, and international CHW advocates, policymakers, and researchers. This manuscript describing our methods addresses this pressing need in the CHW research community.

The Massachusetts CHW Workforce Survey is not the first large-scale assessment of CHWs and their employers in Massachusetts. In the early 2000s, MDPH administered CHW and CHW employer surveys. Significant outreach efforts prior to the administration of the survey identified 806 CHWs and 155 employers (21). Additionally, Section 110 of Chapter 58 of the Acts of 2006 (Massachusetts Healthcare Reform) directed MDPH to conduct a workforce assessment and develop recommendations for a CHW program (33). In 2008, the resulting survey identified 2,932 CHWs across the state (22). In addition to establishing a demographic profile of Massachusetts CHWs, these surveys gathered critical data on roles, opportunities, and barriers facing the CHW workforce that not only drove state priorities but informed our survey design and methods as well (21, 22). Further, the 2008 survey finding that CHWs are most likely to work in CHCs, hospitals, and CBOs informed the development of our sample frame (22).

There have also been national efforts to describe and identify needs and changes in the CHW workforce as well as evaluate potential impacts of certification in the United States. In 2007, the Health Resources and Services Administration (HRSA) of the United States Department of Health and Human Services released a report based on findings of the CHW National Workforce Study (34). This project included a survey of CHW employers in all 50 states and the District of Columbia, which was supplemented with interviews conducted with employers and CHWs in 4 states. This research effort returned a wealth of data, including estimates of the size and demographics of the CHW workforce nationally and in each state (including 2,441 in Massachusetts); CHW income; populations served and roles within their organizations; education and training; and employer characteristics. In addition to the survey and interview findings, this report also exhaustively reviewed CHW certification programs in the United States and outlined requirements, fees, and CHW perceptions of certification (34). Since this landmark report, multiple state and national surveys have also assessed various aspects of the CHW workforce and CHW employers (3, 23–26, 35). Further, a national evaluation of the impact of state-level CHW certification and Medicaid reimbursement on CHW wages and turnover returned mixed results, and it is still unclear how state policies impact CHW employment (25, 36). Nevertheless, this study addressed a critical question related to CHW certification, including potential inequitable impacts by CHW subpopulation (25).

Our research adds to these surveys and evaluations by providing not only survey questionnaires, but other tools we developed as well as detailed information on the development of our sample frames. Further, our methods are to the best of our knowledge one of the few focused primarily on evaluation of state CHW certification. Regarding the sample frames, systematic and replicable construction of the sample frame is critical to conceptualize and generalize the results of the survey and increase the validity of conclusions drawn between survey waves, unlike non-probability sampling frequently employed by other surveys. Further, unclear definitions of the sample frame in previous studies impact generalizability of findings. Collection of data beyond basic CHW demographics is critical to validly evaluate impact of certification-such as organizational characteristics where CHWs are employed and length of time a CHW has worked. Failure to do so can result in significant confounding and bias study conclusions. In contrast, our well-defined sample frame along with extensive individual and organizational data permits more robust interpretation, control of confounding, and conceptualization of findings, which is especially critical given the diverse settings, job titles, and functions of CHWs.

In addition, our implementation of IPW accounts for non-response and differential response within and between survey waves. IPW is a well-documented method of reducing bias in survey research and is essential for drawing robust conclusions from findings compared to unweighted frequencies and percentages often utilized by other surveys. Although no survey analysis method can eliminate bias, our accounting for organizational and community characteristics potentially associated with response probability lessens risk of bias in our findings. The entirety of the process, from survey design, survey administration, construction of sample frames, and statistical analysis (including weighting variables) are replicable in other states and can be leveraged by researchers undertaking evaluations of the CHW workforce. For example, the variables we included in the IPW (e.g., census data, tax documents) and used to construct the sample frame (e.g., UDS HRSA data, list of all acute care hospitals in the state) are largely publicly available. Finally, the forthcoming analysis of our survey results will add to the literature by providing critical information on several important topics related to CHW certification, such as potential adverse and inequitable impacts of certification, CHW integration into healthcare teams, and shifts in CHW employment, including job opportunities, funding, salary, and training.

Our development and administration of the survey resulted in important lessons learned that may be useful for organizations interested in undertaking similar efforts. What cannot be understated is the role CHWs, CHW SMEs, advocacy organizations, and networks played in the development and administration of the survey. Designing valid questions that align with the most pressing needs CHWs face, including potential positive and negative impacts of certification, was crucial to ensure that the results are meaningful and actionable. The qualitative findings were an important component of this, as they aided us in identifying additional outcomes of interest from both the CHW and CHW employer perspectives. Additionally, leveraging networks to ensure as many CHWs are reached as possible and increasing response rates was paramount. Further, applying rigorous, statistical analysis of the data, including accounting for confounding and differential responses, is essential to draw valid, population conclusions within and between waves of the survey. Albeit no survey is without limitations, the extensive analytical efforts we undertook facilitate findings that are robust and replicable.

There are important limitations of this survey to note. While this survey reached a large sample of CHWs and CHW employers in Massachusetts, previous surveys suggest that the number of CHWs in Massachusetts is higher (21, 22, 34). However, this is not unexpected, as we limited the survey to select settings due to limited funding availability and evaluation priorities. As such, our findings will not be generalizable beyond the selected sample frames. Further, all three sample frames are fluid, given the constantly shifting nature of the healthcare and CBO landscape in Massachusetts. The survey only being available electronically may have impacted participation among CHWs and CHW employers with limited internet access or without reliable access to a computer or smart device. Although translation of the survey into Spanish and Portuguese likely permitted us to reach a larger sample of CHWs, some CHWs may have been unable to complete the survey due to limited translations available. Additionally, the first wave of the survey was available only in English, which may impact interpretation between the two survey waves. However, in wave two only a small number of translated surveys were completed (25 of 486 completed surveys). Given this, we feel this likely would not impact interpretation of findings between wave one and wave two. The timeline for wave two of the survey was significantly impacted by the COVID-19 pandemic, and collection of contact information was challenging due to increased telework. Verifying the accuracy of CHWs and CHW employers included in the survey is not feasible. This may have resulted in the inclusion of non-CHWs in the sample; however, our use of fact sheets and call scripts by interviewers while collecting contact information likely minimized this. Our use of a cross-sectional design-albeit repeated and capturing workforce information pre- and post-certification launch-limits causal inference and caution must be taken to not overstate findings. Finally, the CHW Workforce Survey is just one tool to describe the CHW workforce in Massachusetts and monitor the impacts of certification. The MDPH Office of CHWs and partners undertake ongoing evaluation and research efforts that are equally essential, including conducting outreach, focus groups, and key informant interviews. Survey findings should be interpreted in conjunction with these other efforts to provide an accurate, holistic, and nuanced understanding of the Massachusetts CHW workforce and trends.

Nonetheless, the results of the Massachusetts CHW Workforce Survey will provide critical insight into this diverse and important workforce as well as the impacts of certification. The survey design, sample frame development, survey administration, and statistical analysis is the culmination of over 5 years of effort, none of which would have been possible without our partners, CHW advocates, and CHW networks. Further, our conscientious design of the survey tools, rigorous documentation of sample frames, leveraging of local, state, and national CHW networks in outreach, and rigorous statistical analysis demonstrate how robust, replicable findings can be captured on this critical topic. Organizations interested in undertaking similar efforts can use, modify, and improve upon our tools and methods for their own assessments of the CHW workforce and their employers.

Conclusion

There is a notable gap in the literature of studies rigorously evaluating state certification of CHWs. The results of our statistically weighted survey administered in a robustly defined sample frame before and after the launch of Massachusetts CHW certification will answer several important questions. These include whether state certification improves funding, job opportunities, and salaries for CHWs; whether there are potential adverse effects of state certification, such as inequitable access to certification, shifts in workforce demographics, employers adopting requirements for certification, or whether positive impacts are disproportionately benefiting certified CHWs; and whether state certification promotes the integration of CHWs into healthcare teams. Future research should assess similar measures leveraging longitudinal, observational study designs of individual CHWs to further elucidate the impacts of certification. Future research should also assess how CHW certification impacts health outcomes.

Data availability statement

The datasets presented in this article are not readily available because these data are considered confidential by the Massachusetts Department of Public Health Privacy and Data Compliance Office (PDCO). Any data requests must follow processes and requirements of the Massachusetts Department of Public Health and PDCO. Requests to access the datasets should be directed to https://www.mass.gov/how-to/apply-for-access-to-mdph-confidential-records-data.

Ethics statement

The studies involving human participants were reviewed and approved by University of Massachusetts Chan Medical School (UMass Chan) Institutional Review Board. Written informed consent from the patients/participants was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

VN, GS, WWSU, and BB-C oversaw this research project. GH, TM, CS, EG, EM, CA, and BB-C provided subject matter expertise in survey design. VN, WWSU, P-PL, DB, and BB-C designed the statistical analysis plan. P-PL, DB, and BB-C collected and analyzed survey data. All authors contributed to the writing and editing of this manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

EG was employed by Mass General Brigham.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.1043668/full#supplementary-material

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EDITED BY
E. Lee Rosenthal,
Texas Tech University Health Sciences Center El Paso, United States

REVIEWED BY
Limei Jing,
Shanghai University of Traditional Chinese Medicine, China
Joy D. Doll,
Creighton University, United States

*CORRESPONDENCE
Ashley Wennerstrom
✉ awenne@lsuhsc.edu

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Community health worker team integration in Medicaid managed care: Insights from a national study

Ashley Wennerstrom[1,2]*, Catherine G. Haywood[3], Denise O. Smith[4], Dakshu Jindal[5], Carl Rush[6] and Geoffrey W. Wilkinson[7]

[1]Center for Healthcare Value and Equity, School of Medicine, LSU Health, New Orleans, LA, United States, [2]Department of Behavioral and Community Health Sciences, School of Public Health, LSU Health, New Orleans, LA, United States, [3]Louisiana Community Health Outreach Network, New Orleans, LA, United States, [4]National Association of Community Health Workers, Boston, MA, United States, [5]Center for Community Health Alignment, University of South Carolina, Columbia, SC, United States, [6]Community Resources, LLC, San Antonio, TX, United States, [7]Boston University School of Social Work, Boston, MA, United States

Introduction: Community health workers (CHWs) have historically worked in community-based settings. Medicaid managed care organizations (MCOs) are integrating CHWs into their teams, largely to support social determinants of health. Little is known about how teams are structured in these environments or how CHWs and their supervisors perceive CHW roles in MCOs.

Methods: In 2021, two CHW professional associations and a university partnered to conduct a national cross-sectional survey of CHWs working with MCOs.

Results: A total of 146 CHWs representing 29 states and 55 supervisors working in 34 states completed the survey. Although two-thirds of supervisors said only a high school diploma or equivalent was required for hiring, over half of CHWs reported having a bachelors or graduate degree. The majority of CHWs (72.6%) and employers (80%) said CHWs receive training in core competencies. Under half of CHWs reported working with a registered nurse (RN) (45.8%) or social worker (43.8%), and about a third work with a behavioral health (36.3%) or primary care provider (33.6%). Among supervisors, 70.9% identified social workers as CHWs' team members and over half indicated CHW work with RNs (56.4%), behavioral health (54.5%) and primary care providers (52.7%). Over half of CHWs (52.1%) and roughly two thirds (63.6%) of supervisors indicated that CHWs use electronic health records. Roughly 85% of CHWs make referrals and roughly three quarters conduct social screenings. Around half of CHWs said they assist with care planning (54.1%), conduct health screenings (52.1%) or participate in case reviews (49.3%). About three quarters of CHWs (75.3%) and over two thirds of supervisors (67.3%) believed that CHWs are utilized to their full potential. Under three quarters of CHWs (72.6%) and over half of supervisors (54.4%) believe CHWs are equitably compensated for their work.

Discussion: Overall, CHWs roles in MCOs appear to focus on supporting clinical care and making referrals for social issues, rather than addressing community-level concerns. Health plans should ensure that CHWs have the professional freedom to develop community-based solutions to common social needs. MCOs should also ensure that CHWs receive equitable compensation and ensure that CHWs have opportunities for promotion.

KEYWORDS

community health workers (CHWs), Medicaid, managed care organization (MCO), integration, social determinants of health

Introduction

Community health workers (CHWs) are a critical frontline public health workforce defined by their trusted relationships with the communities they serve (1). Operating under a number of job titles including *promotores de salud* and community health representatives, for at least 60 years, they have linked individuals and communities with health and social services, helped people navigate complex systems, and advocated for structural changes in policies related to social determinants of health (2–4). While CHWs' roots are primarily in social justice focused, community-based settings, their work has expanded to a variety of agencies including federally qualified health centers, health departments, and universities, among others (5). There is a nationally recognized set of CHW roles and competencies (6), but programs employing CHWs vary based on community strengths and needs, as well as employer structure, focus, capacity, and funding limitations. Although CHWs are difficult to enumerate, in part due to their various job titles, as of 2021, an estimated 61,000 CHWs worked throughout the United States (7).

In the last decade, as health systems have begun to understand the necessity of addressing social issues, many have moved to integrate CHWs into their care teams. The addition of CHWs to clinical service delivery has been found to improve health outcomes (8) and enhance the patient experience of care (9), and support access to culturally appropriate care (10). For example, integrating CHWs into patient-centered medical homes helps teams better understand patients' backgrounds, challenges, and preferences related to care, which can help improve health outcomes (11). Hospital readmission rates have been reduced among patients who receive care from teams with CHWs (9, 12). An investigation of over a hundred innovative care delivery models revealed that only those using CHWs lowered cost (13). There is also some evidence that adding CHWs to clinical care teams has improved adherence to medications and timely utilization of healthcare services (14).

Researchers seeking to understand factors that promote successful integration have identified clarity of team member roles, clearly defined workflows, and positive culture as important (14, 15). Healthcare team members, including CHWs, have reported that the presence of leaders who support CHWs, as well as a clinic culture that focuses on social, rather than exclusively medical needs, is also critical (16). However, there is some evidence that integration can present challenges to CHWs in maintaining their unique identities as community advocates (17). Healthcare settings tend to value formal education and training above lived experience when hiring CHWs (17), raising questions about whether clinical integration may pull CHWs away from their roots in social justice.

Another area in which CHWs newly find themselves engaged is in Medicaid managed care. Managed care organizations (MCOs), which enter contracts with states to provide health services to Medicaid members, usually on a per member per month basis (18, 19), are highly motivated to achieve two aims in which CHWs are skilled: improving outcomes and reducing costs of care (13, 20–23). MCOs generally have flexibility in their staffing and service delivery models, and some have opted to hire CHWs or contract with external organizations for CHW services. With an increasing emphasis on addressing population health, some states have started to require that MCOs employ CHWs. As of 2021, 10 of 41 states (including DC) that have managed care have instituted some sort of requirement that their contracted MCOs offer CHW services to enrollees. An additional six states indicated that they would also require CHW services in their contracts in the following year (24). As one example, managed care contracts in New Mexico require that at least 3% of enrollees must receive CHW support (25).

Although there is clear momentum for integrating CHWs into MCOs, there is a dearth of national information about MCO priorities for hiring and training CHWs, how teams are structured in these environments, and how CHWs and their supervisors perceive CHW participation in work with MCOs. A few state-level studies provide some important insight. New Mexico-based Molina Healthcare, an early adopter of CHWs employment in an MCO, provided a week of training in many core CHW skills and hired CHWs to support frequent users of the emergency department through education, social support and advocacy, resulting in reduced emergency department visits and overall costs of care (22). In California, providers reported positive experiences when collaborating with CHWs through an MCO initiative that focused on ensuring that CHWs hired held credibility in their communities (26). A 2018 study found that hiring practices and qualifications for CHW employment varied widely among MCOs in Arizona (27) and coordination care organizations in Oregon have found that a lack of understanding of CHW roles among leadership has proved a barrier to CHW integration (28).

This national study aimed to add to the evidence base regarding CHW-MCO integration by surveying CHWs about their experiences working with MCOs. CHW program supervisors working with MCOs were also surveyed, as supervision is critical to successful CHW-team integration (29). Survey questions focused on employer-offered training, CHW responsibilities within their teams, team structure and supervision, reporting structure, and perceptions of team integration. The research team expected that CHWs roles and responsibilities within MCOs would largely be focused on improving clinical outcomes.

Materials and methods

A researcher from LSU Health Sciences Center—New Orleans and CHWs from the Louisiana Community Health Outreach Network (LACHON) and the National Association of Community Health Workers (NACHW) with longstanding relationships collaborated to carry out this study. Two subject matter experts who are founding board members of NACHW provided additional guidance.

The research team based its study methods on previous recommendations for conducting CHW workforce survey research, which include engaging CHWs in survey design, collaborating with CHW networks to distribute the survey, and piloting the survey with CHWs (30). The team collaboratively agreed upon a general list of survey topics including demographics, CHW responsibilities, team structure, and perceptions of team integration. Working from a prior survey (31), the team then selected relevant questions to address the topics identified. Questions and response categories were updated and added, as needed.

The survey was distributed online *via* LACHON's listserv of over 400 CHWs and allies and through NACHW's member newsletter. It remained open from March to July 2021. Over 20 local, state, and regional CHW networks and associations, as well as a dozen national organizations (e.g., policy-focused think tanks and trade organizations for health insurers), were enlisted to support survey distribution. Criteria for participation included: (1) being an adult (18+ years of age) and (2) being employed as a CHW or CHW supervisor at an MCO or at another organization (e.g., a community-based organization) that receives a contract from an MCO to provide CHW services. Interested participants were entered into a raffle for a pre-paid $50 Visa gift card.

Informed consent language was included at the beginning of the survey. The IRB at LSU Health Sciences Center reviewed and approved all research procedures. All data were analyzed using SPSS version 26. Descriptive statistics are reported.

Results

A total of 146 CHWs representing 29 states and 55 supervisors working in 34 states (among 41 with managed care) completed the survey. Among CHWs, over one quarter (27.4%) of respondents were from the West. Just under one quarter (22.6%) reported being from the Midwest. Another 18.5% worked in the Mid-Atlantic region, while 16.4% were from the South, and 15.1% the Northeast. Supervisors often worked across state lines, with 45.5% working in the South and over four in 10 (41.8%) working in the Midwest. Almost one third (30.9%) had work activities in the West, while another 14.5% were in the Northeast. Just 10.9% reported working in the Mid-Atlantic region.

The vast majority of CHWs (87%) and supervisors (76.4%) were women. About four in 10 CHWs were Black, 30.8% were white, and roughly one-quarter were Hispanic/Latinx. Almost six in 10 supervisors were white, just under a quarter were Black, and 7.3% were Hispanic/Latinx. CHWs in this sample most commonly reported having completed some college (37.7%) or a bachelor's degree (37.7%). Nearly three-quarters of the supervisors had a graduate degree. Demographics are summarized in Table 1.

In response to a question about professional requirements for hiring CHWs, just under 10% of supervisors said there was no minimum. About two-thirds of supervisors said a high school diploma or equivalent was necessary. Roughly 9% looked for some college or an associate's degree and about 11% required a bachelor's degree. Table 2 contains these results.

The vast majority of CHWs (72.6%) and employers (80%) reported that CHWs receive training in core competencies. Over half of CHWs indicated that they received training in motivational interviewing and advocacy from their employer. Results are detailed in Table 3.

In terms of team structure, around 8 in 10 CHWs (82.2%) and supervisors (78.2%) indicated that CHWs collaborate with other CHWs. Over half of CHWs and nearly three quarters of supervisors said there was a program manager or director involved. Nearly half of CHWs (47.0%) and about 6 in 10 supervisors (58.2%) said case managers were part of teams. With regard to clinical staff, just under half of CHWs indicated working with a registered nurse (RN) (45.8%) or social worker (43.8%) and about a third said they work with a behavioral health (36.3%) or primary care provider (33.6%). Supervisors more frequently endorsed clinical staff as members of teams, with 70.9% identifying social workers as team members and over half indicating RNs (56.4%), behavioral health (54.5%) and primary care providers (52.7%). Around one in six in both groups indicated that CHWs collaborate with dieticians or nutritionists.

CHWs and employers largely agree that supervision is most commonly provided by a program manager. Fully one quarter of supervisors indicated that social workers supervise CHWs, in contrast to just 5% of CHWs. About one in six

TABLE 1 Demographics of national sample of CHWs and CHW supervisors working with Medicaid managed care organizations.

Variable	CHW (*N* = 146)	Supervisor (*N* = 55)
Age, range	22–72	24–70
Age, mean (SD)	43.8 (12.6)	45.32 (11.9)
	n **(%)**	***n*** **(%)**
Gender		
Woman	127 (87.0)	42 (76.4)
Man	12 (8.2)	10 (18.2)
Prefer not to identify	2 (1.4)	1 (1.8)
No response	5 (3.4)	2 (3.6)
Race/ethnicity		
African American/Black	58 (39.7)	13 (23.6)
White	45 (30.8)	32 (58.2)
Hispanic/Latinx	37 (25.3)	4 (7.3)
Native American/AI	6 (4.1)	0 (0.0)
Asian	2 (1.4)	4 (7.3)
Native Hawaiian/Pacific Islander	1 (0.7)	0 (0.0)
Another race	1 (0.7)	1 (1.8)
Education		
Less than high school	2 (1.4)	0 (0.0)
High school or GED	9 (6.2)	0 (0.0)
Some college or 2-year degree	55 (37.7)	5 (9.1)
Bachelor's degree	55 (37.7)	7 (12.7)
Graduate or professional degree	20 (13.7)	41 (74.5)
No response	5 (3.4)	2 (3.6)

TABLE 2 Minimum CHW education required for hiring as reported by supervisors working with Medicaid managed care organizations.

Education	Supervisor (*N* = 55) *n* (%)
No minimum	5 (9.1)
High school or equivalent	37 (67.3)
Some college	3 (5.5)
Associates	2 (3.6)
Bachelors	6 (10.9)
No response	2 (3.6)

TABLE 3 Employer-offered training for CHWs reported by a national sample of CHWs and CHW supervisors working with Medicaid managed care organizations.

Topic	CHW (*N* = 146) *n* (%)	Supervisor (*N* = 55) *n* (%)
Core competencies	106 (72.6)	44 (80.0)
Motivational interviewing	86 (58.9)	46 (83.6)
Advocacy	73 (50.0)	35 (63.6)
Specific health topic	69 (47.3)	40 (72.7)
Chronic disease	64 (43.8)	35 (63.6)
Navigation	56 (38.4)	29 (52.7)
Peer support	48 (32.9)	26 (47.3)
Leadership	47 (32.2)	22 (40.0)
Medical interpretation	24 (16.4)	8 (14.5)
Languages	10 (6.8)	7 (12.7)

CHWs listed another job title as a supervisor. These included the clinic manger, manager of population health, and chief operating officer.

In terms of work documentation, 72.6% of CHWs and 63.6% of employers indicated that CHWs meet with supervisors. About two thirds of CHWs (63.0%) and half (49.1%) of supervisors reported that CHWs use an internal database to track activities. Just over half of CHWs (52.1%) and roughly two thirds (63.6%)of supervisors said that CHWs use electronic health records. About a third of both groups noted that CHWs use narrative reports. These results are summarized in Table 4.

Making referrals was the most common responsibility that CHWs indicated. About three quarters of CHWs indicated that they receive referrals and conduct social screenings while 85.5% of supervisors endorsed such activities. Over 6 in 10 CHWs and 7 in 10 supervisors said that CHWs conduct home visits. Around half of CHWs said they assist with care planning (54.1%), conduct health screenings (52.1%) or participate in case reviews (49.3%). Supervisors' reports of these activities were all slightly higher. CHWs and employers alike reported that <3 in 10 CHWs provide medical interpretation. Results are reported in Table 5.

Roughly 93 percent of CHWs and supervisors agreed that CHW work is valued at their organization. Nine in 10 CHWs and 94.5% of supervisors agreed that supervisors understand the work CHWs do. Over eight in 10 CHWs and supervisors indicated that CHWs are well-integrated into teams. Almost nine in 10 CHWs believed their teams understand their work (89.0%) and that they are valued (85.6%). Similarly, 83.6% of supervisors agree that CHWs roles are understood and 89.1% believe CHWs are valued by other team members. About three quarters of CHWs (75.3%) and just over two thirds of

TABLE 4 Team structure and reporting methods among a national sample of CHWs and CHW supervisors working with Medicaid managed care organizations.

Variable	CHW ($N = 146$) *n* (%)	Supervisor ($N = 55$) *n* (%)
Team members		
CHWs	120 (82.2)	43 (78.2)
Program manager/director	83 (56.8)	40 (72.7)
Case manager	70 (47.9)	32 (58.2)
RN	66 (45.8)	31 (56.4)
Social worker	64 (43.8)	39 (70.9)
Behavioral health provider	53 (36.3)	30 (54.5)
Primary care provider	49 (33.6)	29 (52.7)
Dietician/Nutritionist	24 (16.4)	10 (18.2)
Other	10 (6.8)	5 (9.1)
CHW supervisor		
Program manager	80 (55.9)	38 (69.1)
Team leader/director	17 (11.6)	12 (21.8)
Senior CHW	11 (7.7)	8 (14.5)
Social worker	7 (4.9)	14 (25.5)
Case manager	4 (2.8)	8 (14.5)
Other	24 (16.4)	7 (12.7)
Methods of reporting CHW activities		
Supervisor meetings	106 (72.6)	35 (63.6)
Database	92 (63.0)	27 (49.1)
Electronic health record	76 (52.1)	35 (63.6)
Narrative reports	51 (34.9)	18 (32.7)
Other	8 (5.5)	2 (3.6)

supervisors (67.3%) believed that CHWs are utilized to their full potential. Just under three quarters of CHWs (72.6%) and over half of supervisors (54.4%) indicated that CHWs are equitably compensated for their work. Among both CHWs and supervisors, about 6 in 10 agreed that CHWs have opportunities for promotion. These results are detailed in Table 6.

Discussion

This study examined the responsibilities, team structure, and perceptions of integration among MCO-supported CHWs and their employers.

The sample of CHW respondents is similar to other studies of CHWs working across sectors, in that the majority are women and people of color (32). In terms of hiring CHWs, MCOs largely report they are not imposing formal educational requirements beyond high school, but the educational level reported by CHWs—with just 7.6% having a high school education or less and over half having a college or graduate degree—suggests that in practice, MCOs prioritize hiring people with higher levels of education. This finding is concerning, given that CHWs' primary qualification has always been community trust. It also suggests that those making hiring decisions may be unfamiliar with CHWs, which is consistent with a prior study (28).

TABLE 5 CHW responsibilities reported by a national sample of CHWs and CHW supervisors working with Medicaid managed care organizations.

CHW responsibilities	CHW ($N = 146$) *n* (%)	Supervisor ($N = 55$) *n* (%)
Make referrals	124 (84.9)	40 (81.8)
Receive referrals for education or other support	111 (76.0)	47 (85.5)
Conduct social screenings	110 (75.3)	47 (85.5)
Receive referrals for home visits	89 (61.0)	39 (70.9)
Assist in developing or coordinating care plans	79 (54.1)	34 (61.8)
Conduct health screenings	76 (52.1)	31 (56.4)
Participate in case reviews	72 (49.3)	35 (63.6)
Provide medical interpreting services	41 (28.1)	16 (29.1)
Other	9 (6.2)	2 (3.6)

Overall, there are several indicators that CHWs roles are being conceptualized in terms of supporting clinical care. Supervisor responses to the types of training CHWs receive, which largely included CHW training in skills such as motivational interviewing, chronic disease, and navigation, are directly related to helping patients manage chronic conditions and, ultimately, reducing costs of care. In addition, CHWs' use of electronic health records, along with their participation in conducting case reviews and developing care plans alongside clinically trained providers demonstrate that CHWs are largely focused on improving health outcomes among individual Medicaid members. This medicalized approach suggests that CHWs may have limited time to engage in more community-based, social justice work that is the historical hallmark of the profession (2, 4), and appears to be consistent with a prior study of coordinated care organizations that found individually-focused CHW activities were more common than community-level advocacy (28).

The finding that CHWs make and receive referrals is consistent with nationally recognized CHW roles (6). Although

TABLE 6 Perception of CHW value and team integration among a national sample of CHWs and CHW supervisors working with Medicaid managed care organizations.

CHW responses $N = 146$				Supervisor responses $N = 55$			
Statement	Agree completely/ somewhat *n* (%)	Disagree completely/ somewhat *n* (%)	N/a *n* (%)	Statement	Agree completely/ somewhat *n* (%)	Disagree completely/ somewhat *n* (%)	N/a *n* (%)
My organization values the work that I do	135 (92.5)	7 (4.8)	0 (0.0)	My organization values the work CHWs do	51 (92.7)	2 (3.6)	0 (0.0)
My supervisor understands the work that I do	131 (89.7)	9 (6.2)	1 (0.7)	CHWs' work and roles are understood by the individuals who supervise them	52 (94.5)	0 (0.0)	0 (0.0)
The team I work with understands the work I do	130 (89.0)	12 (8.2)	0 (0.0)	CHWs' work and roles are understood by the teams they work with	46 (83.6)	7 (12.7)	0 (0.0)
I am a valued member of the teams I work with	125 (85.6)	14 (9.6)	2 (1.4)	CHWs are valued members of the teams they work with	49 (89.1)	4 (7.3)	0 (0.0)
I am well-integrated into the team at my organization	122 (83.6)	18 (12.3)	1 (0.7)	CHWs are well-integrated into team	45 (81.8)	7 (12.7)	0 (0.0)
I am utilized to my full potential	110 (75.3)	31 (21.2)	1 (0.7)	CHWs are utilized to their full potential	37 (67.3)	15 (27.3)	1 (1.8)
I am equitably compensated for my work	106 (72.6)	34 (23.8)	1 (0.7)	CHWs are equitably compensated	30 (54.5)	20 (36.4)	3 (5.5)
I have opportunities for promotion at my organization	87 (59.6)	44 (30.1)	11 (7.5)	CHWs have opportunities for promotion	35 (63.6)	14 (25.5)	4 (7.3)

Totals may not sum to 100% due to missing responses.

a study in 2018 found limited CHW engagement in conducing assessments (27), the finding that CHWs are now conducting screenings for social needs is unsurprising, given the increasing interest in addressing social determinants of health and that some state Medicaid contracts specifically outline that role (24). As MCOs continue to engage CHWs in their service delivery models, it will be critical to ensure that CHWs' efforts to address social determinants of health are not limited to merely making referrals for social issues identified through screening. CHWs will need freedom to not only develop relationships with agencies that receive member referrals, but also to develop community-based solutions to common social needs. For example, CHWs may collaborate with one another and local leaders to develop a food bank in an area with limited resources. CHWs working in teams have identified the opportunity to network as being critical to their roles (33). Furthermore, ensuring that CHWs have the flexibility to respond to community-level issues could help address the substantial proportion of CHWs and supervisors who report that CHWs are not utilized to their full potential.

It is encouraging that CHWs and supervisors alike generally perceive that CHWs roles are understood and valued by fellow team members. However, it is concerning that over one quarter of CHWs do not feel that CHWs are equitably compensated, as do nearly one half of supervisors, who likely have greater insight than CHWs into compensation levels for various positions. Broadly, CHW contributions have often been conceptualized in terms of return on investment (i.e., how does the cost of CHW salaries, benefits, and supervision compare to costs saved through reduced health care services use?), and MCOs may be developing CHW salary scales based on this approach. If so, they would be wise to consider that much of the value CHWs bring in terms of addressing health related service needs issues (e.g., education, housing, food, transportation, re-entry) for individuals and families may not immediately be reflected in healthcare costs. As health financing reform shifts risk to providers and drives care "upstream," equitable compensation for CHWs, reflecting their value in addressing social determinants of health and promoting health equity, should be considered a prudent investment. Fair compensation may also be an important step toward addressing the inherent power differential between CHWs and clinically trained providers.

In addition to concerns about salaries, health plans should make efforts to address the substantial proportion of CHWs and supervisors who do not perceive that CHWs have opportunities for promotion. It is worth noting that CHWs are largely being supervised by people who are not CHWs, and likely do not have experience in the field. MCOs might consider collaborating with CHWs to develop career pathways (e.g., promotion to CHW supervision or program management) to ensure that CHWs do not perceive themselves to be in "dead end" jobs.

Limitations

This study has several limitations. Because it is a cross sectional study, it is not possible to draw causal inferences. The sample size is also relatively small. Due to the survey distribution method (i.e., requesting that CHW networks share the survey with their members), it is not possible to calculate a response rate because we cannot ascertain the number of CHWs who received the survey and met the inclusion criteria. There may also be some selection bias if the group that was most likely to receive the survey—those who are members of a professional network—has different characteristics than those unaffiliated with CHW networks. Statistical testing to assess differences between supervisors and CHWs was not conducted because members of each group did necessarily work at the same organizations (i.e., the supervisors who responded may not have supervised the CHWs who did). Furthermore, CHWs and supervisors are substantially different and would reasonably be expected to have different perspectives. Despite these limitations, the sample was nationally representative, and it sheds light on a topic that is under-studied.

Conclusion

Overall, CHWs roles in MCOs appear to focus on supporting clinical care and making referrals for social issues, rather than addressing community-level concerns. Health plans should ensure that CHWs have the professional freedom to develop community-based solutions to common social needs. MCOs should also ensure that CHWs receive equitable compensation and ensure that CHWs have opportunities for promotion.

Data availability statement

The datasets presented in this article are not readily available to protect the confidentiality of participants. Requests to access the datasets should be directed to awenne@lsuhsc.edu.

Ethics statement

The studies involving human participants were reviewed and approved by LSU Health Sciences Center—New Orleans IRB. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

AW: conceptualization, methodology, investigation, formal analysis, writing—original draft, and funding acquisition. CH and GW: conceptualization, methodology, and data curation. DS: conceptualization, methodology, data curation, and writing—review and editing. DJ: data curation, writing—original draft, and writing—review and editing. CR: conceptualization, data curation, and writing—review and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

CR was employed by Community Resources, LLC.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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EDITED BY
Christiane Stock,
Charité Medical University of Berlin, Germany

REVIEWED BY
Maia Ingram,
University of Arizona, United States
Jennifer Hambrick,
Catholic Charities Archdiocese of
Galveston-Houston, United States

*CORRESPONDENCE
Ragavi Jeyakumar
✉ r.jeyakumar@student.unsw.edu.au

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"We're on the ground, we know what needs to be done": Exploring the role of Aboriginal Health Workers in primary health care

Ragavi Jeyakumar[1,2]*, Bindu Patel[1], Julieann Coombes[1], Ty Madden[1] and Rohina Joshi[1,3,4]

[1]The George Institute for Global Health, University of New South Wales, Sydney, NSW, Australia, [2]Faculty of Medicine and Health, University of New South Wales, Sydney, NSW, Australia, [3]School of Population Health, University of New South Wales, Sydney, NSW, Australia, [4]The George Institute for Global Health, New Delhi, India

Background: Aboriginal Health Workers (AHWs) are core providers of primary health care (PHC) for First Nations peoples in Australia. However, the national AHW workforce is aging and in short supply. There is a poor understanding of the factors contributing to this attrition from the perspectives of AHWs themselves. This study aimed to systematically explore the current functioning and sustainability of AHWs in NSW PHC by amplifying AHW voices.

Materials and methods: This study was co-designed with three Aboriginal health services in NSW. It included a literature review exploring the role of AHWs in NSW, and yarns with AHWs and their supervisors at participating services. Yarning is an Indigenous approach to knowledge generation centered upon storytelling. The yarns were guided by the USAID-developed Community Health Worker Assessment and Improvement Matrix. Yarn transcripts were analyzed using cyclical thematic analysis to identify key facilitators and challenges for AHW practice.

Results: The yarns highlighted five categories of change that are required to ensure AHW sustainability: community connection, recognition, value, support, and an inclusive health system. The yarns revealed that there are both service- and system-level factors influencing each of these categories of change.

Conclusions: The lived experiences of AHWs in NSW emphasize five key categories of change that are required to ensure workforce sustainability. It is evident that a system-wide paradigm shift to better include holistic approaches to health is necessary to truly ensure sustainability. Co-designing similar studies with ACCHOs across NSW can help inform this change.

KEYWORDS

Aboriginal Health Worker, community health worker, primary health care, workforce, sustainability

1. Introduction

Since the establishment of the first Aboriginal Community Controlled Health Organisation (ACCHO) in 1971, Aboriginal Health Workers (AHWs) have played a significant role in the provision of primary health care (PHC) for Aboriginal and Torres Strait Islander peoples (1). Australia's diverse First Nations peoples hold a holistic understanding of health, encompassing health of the body, mind, spirit, and land that is best served by Aboriginal community controlled organisations (2). While mainstream PHC in Australia is typically delivered by general practice clinics, PHC for First Nations populations within Australia is driven by 196 Aboriginal PHC services operating nationally. Aboriginal PHC services include both 144 ACCHOs and 52 state-run Aboriginal Medical Services (3). The services seek to provide whole-of-community, culturally safe, accessible PHC for First Nations peoples (4). AHWs are based within these services and play a central role in achieving these aims (5).

AHWs are health workers that are members of the First Nations communities where they work that have been trained to support holistic PHC provision for their communities (6). The AHW role is one of few positions within the Australian health workforce that is exclusively occupied by First Nations peoples (5). As such, they are instrumental in creating a culturally safe and responsive health system (2, 5). As members of the communities in which they practice, AHWs have an innate understanding of the strengths, concerns and lived experiences of the people they serve, and this uniquely positions them as "cultural brokers" between the community and the health system (6). Due to the community-specific nature of their practice, there is great variability in the roles performed by AHWs based on community needs, with responsibilities ranging from clinical task-sharing to community education (7–9). Studies have shown that AHWs improve the uptake of preventive services, screening programs and chronic disease treatment in their communities by facilitating culturally appropriate care, reducing communication gaps, and enhancing referral linkages (10–14). Additionally, beyond improving measurable outcomes, AHWs are able to create cultural change within mainstream health services. They have been seen to act as patient advocates and clinician educators to reconcile the Western biomedical model of healthcare with First Nations understandings of health (9, 15). Government health strategies increasingly position AHWs as central to "Closing the Gap" and place high expectations on the workforce's capacity to achieve universal health access for First Nations peoples (5, 16–18). Indeed, the Australian Government's "Primary Health Care 10 Year Plan" aims to have a "continually growing" Aboriginal health workforce in 10 years "to support the health needs of Aboriginal and Torres Strait Islander peoples"(18).

As of 2020, there were 842 AHWs working across the 196 Aboriginal PHC services nationally (3). Over 25% of these AHWs were based in Aboriginal health services in New South Wales (NSW), where AHWs work as members of an integrated healthcare team to provide "flexible, holistic and culturally sensitive health services" to Aboriginal communities (3, 19). There are four broad categories of AHW recognized in NSW: Aboriginal Health Worker, Aboriginal Health Practitioner, Senior Aboriginal Health Worker, and Principal Aboriginal Health Worker (20). There are many specific AHW roles within each of these categories, and their responsibilities and training requirements are prescribed by the NSW Health Aboriginal Health Worker Guidelines (20). The typical position of AHWs within an Aboriginal PHC service is summarized in Figure 1. This structure was synthesized from a number of sources (3, 4, 19–24) and confirmed through our research work. It should be noted that due to the community-dependent nature of ACCHOs, there is no fixed state-wide structure for AHWs within ACCHOs and variation is expected (24).

It is increasingly clear that the sustainability of AHWs in the NSW and Australian workforce is threatened, with studies reporting of low self-worth and high levels of stress and attrition amongst AHWs (6, 10). The national AHW workforce is stagnant and aging, with the number of AHWs falling from 221 to 207 staff per 100,000 First Nations people between 2006 and 2016, and the proportion of AHWs aged 55–64 rising by 7.5% in the same period (10). This presents a significant threat to the ongoing safety of PHC for First Nations peoples. Several factors have been speculated to contribute to this phenomenon. Most significantly, it has been noted that there remains a pervasive lack of understanding of the unique skills, roles, and value of AHWs (1, 6, 25–28). In daily operations, this has been reported to manifest as a lack of respect for the AHW role amongst managers and other health professionals (26, 27) and poor role boundaries in the workplace (9) leading to the frequent relegation of AHWs to "menial" administration and transport tasks (28, 29). At an institutional level, it has been identified that the lack of value for the role has impeded the inclusion of AHWs in formal workforce planning, led to lack of competitive pay, and prevented the establishment of adequate, sustainable funding structures (7, 8). For instance, at present, AHW salaries in ACCHOs are not regulated statewide and are determined through enterprise bargaining processes with individual ACCHOs (9).

Few studies have sought to holistically explore the day-to-day functioning, strengths, and limitations of the AHW workforce. Most literature on AHWs in Australia has focussed on evaluating the role of AHWs in one-off, novel interventions (12, 14, 28–30), rather than within the PHC system itself. Indeed, no paper or organizational policy clearly describes the position of AHWs within PHC. Any studies which have investigated the typical functioning of the AHW program have tended to focus on isolated components, such as defining the role's responsibilities (8) or investigating its support structures (29). Additionally, AHW voices have been notably absent from almost all investigations (9). A comprehensive understanding of the position, strengths, and limitations of the current AHW PHC program, from the perspectives of the AHWs that work within it, is essential to ensuring the role's sustainability. This knowledge has the potential to strengthen the AHW program by identifying its key supports and challenges. Studies of AHWs that are founded upon decolonised research methodologies and Indigenous approaches to data gathering could effectively gather such knowledge (31). No such study has been conducted in the state of NSW, which contains 37 of the 143 ACCHOs currently operating in Australia (32). As of 2020, there were 220 AHWs working in Indigenous-specific PHC across NSW (3).

There is growing interest in the use of community health worker (CHW) programs to address health inequity in high-income countries internationally (33, 34). For instance, the Australian Government has recently committed to trialing a "Rural Area Community Controlled Health Organisation" model of health delivery in remote areas, potentially involving rural CHWs, and have increased use of CHWs for refugee populations (18). Understanding the factors which contribute to a sustainable AHW workforce will strengthen the existing AHW program. Additionally, it could help guide the expansion and implementation of other CHW programs. Therefore, the overall aim of this study was to work with AHWs to uncover their knowledge in a culturally safe manner and to enable their lived experiences to guide the development of a safer, fairer health system for all Australians. The study sought to use Indigenous research methodologies, such as yarning, to achieve this aim.

Abbreviations: ACCHO, Aboriginal Community Controlled Health Organisation; AHW, Aboriginal health worker; CHW, Community health worker; CHWAIM, The Community Health Worker Assessment and Improvement Matrix; NSW, New South Wales, Australia; PHC, Primary health care; WHO, World Health Organisation.

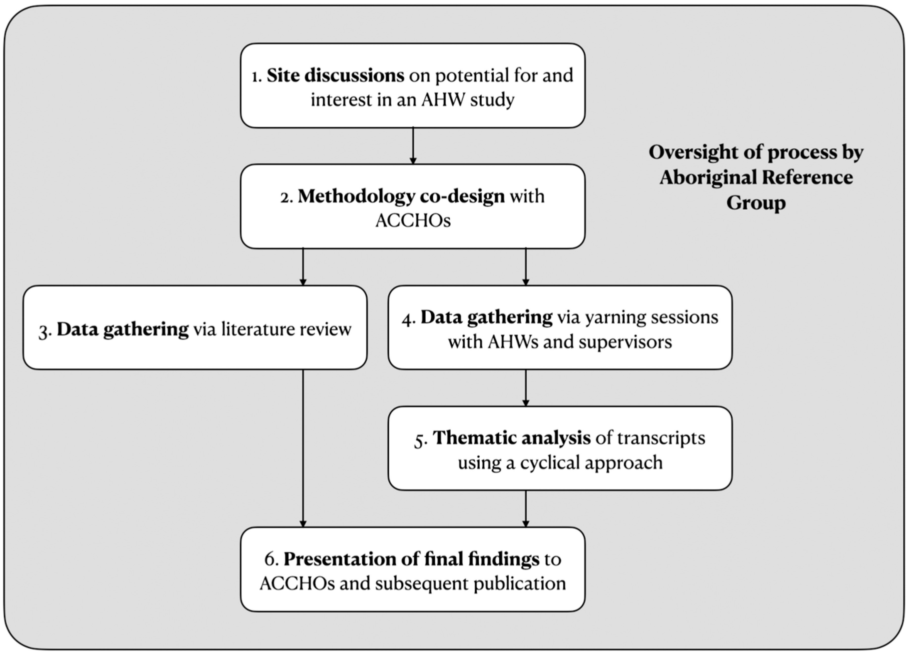

FIGURE 1
Study design. This flowchart shows the steps involved in "Exploring the Role of Aboriginal Health Workers in PHC in New South Wales". AHW, Aboriginal Health Worker; ACCHO, Aboriginal Community Controlled Health Organisation.

2. Materials and methods

We used the Community Health Worker Assessment and Improvement Matrix (CHWAIM) which is an internationally recognized tool that has been developed to guide the systematic analysis of CHW programs (Table 1) (35). The CHWAIM examines ten components of a CHW program that are evidenced to be essential to their functioning (35). By exploring each of these components, the CHWAIM can comprehensively uncover the strengths and limitations of any CHW program and systematize understanding of its present workings.

This study aims to apply the CHWAIM to systematically explore the functioning and sustainability of AHWs in NSW PHC, by amplifying AHW voices. We were interested to understand the current role of AHWs in PHC in NSW and the day-to-day and systematic factors that impact the AHW program sustainability.

2.1. Setting

This study involved three health services operated by two ACCHOs in New South Wales (NSW). All three sites were in regional NSW and collectively employed 21 AHWs. NSW was selected as a setting for the study due to lack of existing AHW research within the state and existing research relationships. Over 25% of practicing AHWs in Australia are based in NSW and the governance of AHWs is similar to other states (3).

2.2. Study design

This study was co-designed with the participating ACCHOs in a series of phases as summarized in Figure 2. The study's research team consisted of Aboriginal (JC, TM) and non-Indigenous (RaJ, RoJ, BP) researchers. The team was guided by an Aboriginal Reference Group composed of First Nations researchers and community members with diverse experiences within the health sector.

Our study aimed to understand the current role of AHWs in PHC in NSW and the day-to-day and factors that impact AHW program sustainability through the voices of AHWs. These aims were met through yarning at the participating health services.

2.2.1. Site discussions

In the initial research phase, JC contacted two ACCHOs and TM visited 15 ACCHOs across NSW to discuss their interest in this study. We sought feedback regarding the plan's value, viability, and appropriateness. This feedback was used to finalize the study aims and design. While numerous ACCHOs contributed to the pre-study consultation process, data was only collected at three sites due to time constraints.

2.2.2. Methodology co-design

A central aim of this study was to amplify AHW voices. The research team and participating communities identified that to achieve this, our work had to be founded on culturally safe methods of knowledge creation. Yarning, a validated Indigenous research methodology (31, 36–40), was consequently selected as our data collection method. Yarning is an approach to qualitative

TABLE 1 CHWAIM assessment framework (35).

Role and recruitment	How the community, CHW, and health system design and achieve clarity on the CHW role and from where the CHW is identified and selected
Training	How pre-service training is provided to the CHW to prepare for his/her role and ensure s/he has the necessary skills to provide safe and quality care; and, how ongoing training is provided to reinforce initial training, teach CHWs new skills, and to help ensure quality
Accreditation	How health knowledge and competencies are assessed and certified prior to practicing and recertified at regular intervals while practicing
Equipment and supplies	How the requisite equipment and supplies are made available when needed to deliver expected services
Supervision	How supportive supervision is carried out such that regular skill development, problem-solving, performance review, and data auditing are provided
Incentives	How a balanced incentive package reflecting job expectations, including financial compensation in the form of a salary, and non-financial incentives, is provided.
Community involvement	How a community supports the creation and maintenance of the CHW program.
Opportunity for advancement	How CHWs are provided career pathways.
Data	How community-level data flow to the health system and back to the community and how they are used for quality improvement
Linkages to the national health system	The extent to which the Ministry of Health has policies in place that integrate and include CHWs in health system planning and budgeting and provide logistical support to sustain district, regional and/or national CHW programs.

This table outlines the Community Health Worker Assessment and Improvement Matrix (CHWAIM), developed conjointly by the World Health Organisation and the United States Agency for International Development Healthcare Improvement Project in 2011. The CHWAIM outlines 10 components evidenced to contribute to highly functional CHW programs. It was developed as part of a toolkit that also includes questionnaires, worksheets, and recruitment forms to aid in the assessment and improvement of CHW programs (35).
CHW, Community Health Worker.

data gathering that centers storytelling in conversation (36). Unlike questionnaires or surveys which are fixed according to the researchers' agenda, yarns are guided by the stories and lived experiences of participants. Storytelling is a key component of First Nations pedagogy and its use in yarning allows research to be conducted in a manner that assumes responsibility, reciprocity, and respect for Aboriginal Ways of Knowing, Being, and Doing (31, 40, 41).

The yarning process in this study sought to gather stories from AHWs about their lived experience in the field and stories from AHW supervisors about the governance of AHWs in NSW. Ng'andu and Bessarab outline that yarning sessions in research progress through four different types of yarns: social, research topic, collaborative and therapeutic (Figure 3) (36). Firstly, there is social yarning: an unstructured conversation that takes place before the research occurs to build trust and accountability by each participant and researcher identifying themselves and their experiences. Subsequently, there is research topic yarning to collect information pertaining to the research question through the participants' stories. The research topic yarn can transition to collaborative yarning in which information about the research project and ideas are shared, and to therapeutic yarning which takes place when a participant discloses traumatic or sensitive information. Throughout the process, the researcher transitions primarily to the role of a listener, to help affirm and facilitate the participant's meaning-making in voicing their story.

A yarn guide was developed in conjunction with the ACCHOs to frame the research topic yarns in this study. The guide (Supplementary material) was based on the CHWAIM to help ensure that the key aspects of the AHW program were addressed in each yarn.

2.2.3. Yarning

Yarns were conducted with two groups of staff at each ACCHO: AHWs, and AHW supervisors. Group yarns were conducted with all participating AHWs at each site. Separate supervisor yarns were conducted with either individuals or pairs of supervisors. A total of 13 AHWs (62% of all employed AHWs) and five supervisors participated in the study, and a total of seven yarns were conducted.

The ACCHOs which consented to participate in the study recruited participants *via* email. Administrative staff shared email invites with all AHWs at each site and interested AHWs returned written consent. The yarns involved AHWs representing different roles and career stages at each ACHHO. Relevant supervisors were invited by the CEO of each ACCHO. All nominated supervisors participated in the study.

Due to travel restrictions imposed by the COVID-19 pandemic, in-person data collection was not possible. Consequently, all yarn sessions were held in a hybrid model, with researchers and an Aboriginal research associate (TM) facilitating remotely *via* Zoom, and ACCHO staff meeting in person. All yarns were audio-recorded with permission. The yarns lasted between 50 and 91 min and explored the topics outlined in the CHWAIM yarn guide (Supplementary material). Audio recordings of the yarns were deidentified and transcribed verbatim.

2.2.4. Data analysis

The yarn transcripts were explored using a cyclical approach to thematic analysis (Figure 4). This approach firstly involved Aboriginal (JC, TM) and non-Indigenous (RaJ, RoJ, BP) researchers examining the transcripts together. Data was analyzed using a mixed approach, which involved deductive and inductive identification of key themes iteratively over several rounds and categorized into codes and sub-codes using NVivo V.12 (QSR International, 2015). Secondly, the preliminary themes emerging from this process were summarized and sent back to the ACCHOs for review. A discussion session was then organized *via* Zoom to facilitate collaborative yarning between ACCHOs and the research team. Following this discussion, themes and codes were again refined by the research team. This cyclical approach presented an analytical parallel of yarning methodology in generating findings that were grounded in Aboriginal Ways of Knowing, Being, and Doin g(42).

2.2.5. Presentation of findings

The key findings from the study were summarized in a plain-language results paper and presented back to each site in an online workshop for participant feedback.

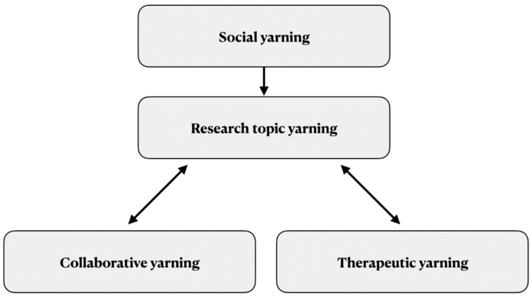

FIGURE 2
The yarning research process (36). This flowchart created by Ng'andu and Bessarab outlines the four different types of yarns that are involved in research through yarning (36). Firstly, there is social yarning: an unstructured conversation that takes place before the research occurs to build trust and accountability by identifying yourself and your experiences. Subsequently, there is research topic yarning to collect information pertaining to the research question through the participants' stories. The research topic yarn can transition to collaborative yarning, in which information about the research project and ideas are shared, and to therapeutic yarning, which takes place when a participant discloses traumatic or sensitive information. The researcher transitions to the role of a listener, to help affirm and facilitate the participant's meaning-making in voicing their story.

2.3. Ethics approval

This project received approval from the UNSW Human Research Ethics Committee (reference: HC210247) and the Aboriginal Health and Medical Research Council Human Research Ethics Committee (reference: 1800/21).

3. Results

3.1. Facilitators and challenges for sustainability

The yarns highlighted several core facilitators and challenges for AHW sustainability in NSW. These facilitators and challenges can be mapped to seven of the 10 components of the CHWAIM, as summarized in Table 2.

3.1.1. Role and recruitment

AHWs at each site described their roles as broad and flexible, encompassing clinical, administrative, and client advocacy duties. Every AHW emphasized that their primary motivation was to support their community. The flexibility inherent in the AHW role allowed them to adapt to best serve the needs of the community and the community-controlled service in which they worked.

> *"We have the general responsibilities—advocacy, supporting mob, accessing services, and coordinating clinics is probably a few of our main responsibilities here. But we have become so flexible that we're responsible in all aspects of the daily running of the clinic, whether that's jumping up, supporting transport, going to pick up a client to sitting with them within a consult and advocating for them in that part… so that we can still maintain a professional flow of service for our community because we know if one falls down, generally we all fall down."*

However, AHWs described that the variability of their role meant that day-to-day work was often highly fragmented. This led to separation within AHW teams and contributed to burnout.

> *"I'm the only one that does the Brokerage in CCS, so I'm burnt out 200% all the time. Like, yeah, so it's hard."*

Further, a major concern voiced in every yarn was the limited capacity for decision-making and clinical practice within the AHW role. This limited scope failed to recognize the capabilities of AHWs. Supervisors highlighted that expanding this scope could help fill service gaps.

> *"We're on the ground, we know what needs to be done."*
>
> *"They're trained to do much more than what they're actually doing… We probably could utilize our Aboriginal health workers in much more efficacy across the service if the scope of practice was broadened for the health workers. For example, the nurses that are currently doing vaccinations [are] being absolutely smashed. But I've got two nurses currently on that could have been opportunities for Aboriginal health workers to be supporting them in that process."*

The yarns revealed that recruitment at each site centered on internal processes. Recruitment for entry-level AHW positions was typically from other areas of the ACCHO such as reception or transport. Management positions were also often advertised internally at first. This approach was recognized by participants as a clear way to demonstrate value for AHWs and their communities.

> *"There's a policy here where we give people opportunities to bring people in as trainees, maybe at reception, and then they'll often move on to other roles within the organization … They're given, not preferential treatment, but they're notified about those vacancies and encouraged to apply. There are a lot of our staff who've been here for a long time, and they've worked their way through the organization."*

Alternately, supervisors described that the viability of external recruitment was dependent on the reputation of the ACCHO within the community. A positive community perception was essential to ensuring that new AHWs could be attracted.

> *"We're struggling to try and find people for roles, as well … if they've heard how people have been treated in the past or somebody has worked here and they haven't liked it and they've gone back out, Koori grapevine is faster than Facebook, I'll tell you."*

3.1.2. Training

AHWs received financial support from ACCHOs for both mandatory and additional training. They described that this support helped them feel valued by the organization.

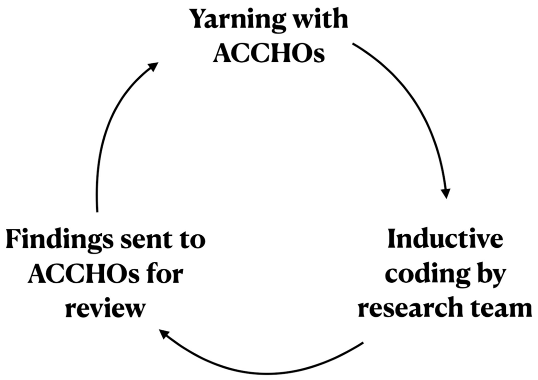

FIGURE 3
A cyclical approach to thematic analysis. This flowchart summarizes the cyclical approach to analysis utilized in this study. ACCHO, Aboriginal Community Controlled Health Organisation.

> *"They give us the opportunity to do a lot of training and we just take it on board and go from there with it. And there's that support from our service, our CEO and clinical service manager and those people that are involved and that's something that they look at, just empowering Aboriginal health workers … whatever we like, we'll just send through requests and if it's relevant they'll give us the funding to do that and it's really great."*

However, both AHWs and supervisors identified that beyond funding, other forms of support, such as academic mentoring and paid leave were also required to successfully complete training. This support was less commonly provided.

> *"We've got to give a lot of staff a hell of a lot of support to get through those courses… The majority of local people that we employ have limited education and no qualification, no skills. So they come in very raw and a lot of them have limited literacy and numeracy skills, and that places a high expectation on them to get skilled."*

Further, access to additional training was typically provided on an individual basis, and AHWs highlighted that a clear, formalized rationale could aid in career planning. However, supervisors explained that the unsustainable funding of ACCHOs made it difficult to implement a consistent training budget.

3.1.3. Supervision

Despite not being included in formal supervision structures, senior AHWS played a vital role in the professional and cultural mentorship of newer AHWs at each site. They helped facilitate a sense of "family" that was central to job satisfaction and cultural safety for AHWs in the workplace. However, AHWs described that there was poor communication between AHWs and official management teams. While several communication pathways had been planned at each site,– from formal meetings to informal team huddles–participants reported that these were often abandoned in favor of competing demands.

> *"Facilitator: Do you guys feel like your voices are heard on an organizational level?*
> *P1, P2, P3: No.*

> *P4: Can you tell by the silence from us? Awkward silence… There's got to be more communication between the mob upstairs and us down here too as well."*

Ultimately, AHWs described mechanisms to support workplace wellbeing and address concerns such as burnout and work-life balance were lacking.

> *"It shouldn't be up to the individual to really try to identify what needs to be done for our wellbeing. You know we're already trying to find those solutions for our community, for their wellbeing, so you know the expectation from us would be having our managers, having our supervisors identify key areas of supports within wellbeing and implementing that."*

3.1.4. Incentives

AHW salary in ACCHOs is guided by a Commonwealth award. At each site, AHWs were able to enter "enterprise bargaining" processes to negotiate their pay above this award. However, despite these processes, every participant identified that a key factor impeding AHW sustainability was the lack of adequate pay. Firstly, AHW salary was not commensurate for the work that they perform in enabling clients to access all billable services and providing constant community support.

> *"We're not really paid for what we do. We're paid on the contract that we sign but with working in community, we don't switch off at five o'clock … it's an ongoing role within the community and I think that needs to be, well not so much reflected because you can't really put a price on that kind of service outside of the work hours, but I think that needs to change."*
>
> *"Whilst they don't sign off on the [health assessment], the health worker will do most of the underlying work to generate that information, so without the health worker a doctor would be doing that, and we'd be paying them three times the amount, to get that same payment."*

Secondly, AHW salary was not competitive with other roles available to AHWs outside of ACCHOs.

> *"A lot of them, you know, have families, they have kids and that, they've got a mortgage, they've got a car and it's, they can't afford it on the pay they get, well … whatever pays best next … And less stress. Woolworths even sometimes."*

This was exacerbated by the fact that the award does not account for the variations in pay grade between different AHW roles, most notably for Senior AHWs. Additionally, supervisors described that bargaining processes and unsustainable funding lead to a lack of consistency and transparency in AHW salaries between ACCHOs.

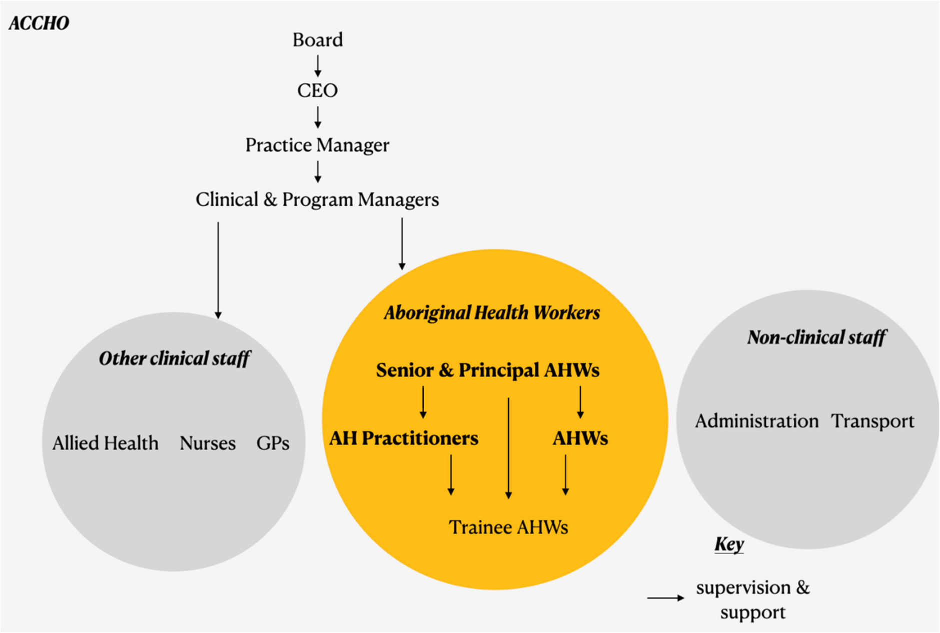

FIGURE 4
Position of AHWs in PHC in NSW. This chart summarizes the typical position and governance of AHWs (in the orange circle) within a typical NSW ACCHO. Other health staff are shown in the gray circles. The arrows signify the direction of supervision, starting with the Board. AHW, Aboriginal Health Worker; ACCHO, Aboriginal Community Controlled Health Organisation.

TABLE 2 Facilitators and challenges for AHW sustainability at participating sites.

	Facilitators	Challenges
Role and recruitment	• Adaptability of role to community and ACCHO needs • Internal recruitment to upskill and recognize community	• Fragmentation of work • Limited decision-making and clinical capacity • External recruitment dependent on community perception
Training	• Financial support for mandatory and additional training	• Ensuring holistic support for training • Lack of formalized, sustainably funded training pathways
Supervision	• Informal cultural mentorship by senior AHWs	• Embedding pathways for regular communication with official management • Embedding wellbeing support
Incentives	• Regular enterprise bargaining processes	• Lack of commensurate, competitive pay • Lack of adequate detail in award
Community involvement	• Strong AHW-community connection • Consultations to maintain ACCHO-community connection	• Constant AHW accountability to community
Opportunity for advancement	• Internal pathways for AHW advancement	• Lack of formalized advancement pathways • Fear of community disconnection with advancement
Linkages to the national health system	• Brokerage between community and national health system	• Lack of value for AHWs in Western system • Lack of value for ACCHOs in Western system

This table summarizes the key facilitators and challenges for AHW sustainability that were identified in our yarns. These key factors align with seven of the 10 components of the CHWAIM. The remaining three components (Accreditation, Equipment and supplies, and Data) were not prominent in the gathered stories of the AHWs.
AHW, Aboriginal Health Worker; ACCHO, Aboriginal Community Controlled Health Organisation

3.1.5. Community involvement

Community connection was identified to be the core driver of AHW practice. Every yarn emphasized that AHWs were inextricably linked to their community and a sense of positive community impact was central to AHW job satisfaction.

"We're here for our community. To provide the holistic care for our community."

"It makes us feel good at the end of the day that we done something for them, you know. And that's the only recognition that I'd like to get–from my patients."

Regular formal and informal consultations helped maintain a close, positive connection between the ACCHO and the community. However, such strong community ownership of the AHW program led to AHWs being held accountable by the community outside of work hours. The subsequent lack of work-life boundaries was identified to be a major contributor to AHW burnout.

> *"Being a health worker is not a 9:00 to 5:00 job. It's a 24-seven job so they have to have a real commitment to the job, but it impinges on their personal life . . . they are held accountable by their community, and it seems the more dedicated they are, and the more passionate they are, the more they are under the scrutiny and criticism of their community. That's very difficult."*

3.1.6. Opportunity for advancement

Each site was committed to the advancement of AHWs and their community through training and internal promotions. The typical pathway of promotion was from reception and other administrative roles to AHW, then to AHP, and in a limited number of cases, to management positions. However, these pathways were not formalized and the requirements for advancement were not explicated.

> *"There is a pathway, but it's not an official pathway, it's not a structured pathway. . . initially we'll advertise internally before we look outside, but we won't actually say, because you've done so many years and you've got this particular qualification, that you must get this particular role."*

Further, AHWs expressed disinterest in "progressing" to a management role due to the associated disconnection from the community, which is the core motivator for their work.

3.1.7. Linkages to the national health system

Participants at each site recognized the importance of AHWs in linking clients to other health services. Every AHW expressed great satisfaction at being able to broker the required care for their community. However, the yarns emphasized that the Western biomedical model of health which dominates healthcare in Australia is limited in its ability to support and value the work of AHWs and ACCHOs. Supervisors described that the focus on clinical practice and "mainstream" healthcare services has created an unsustainable, incomplete model of funding for ACCHOs and their AHWs. Every yarn highlighted the lack of value and importance for the work of AHWs amongst policymakers and other health professionals.

> *"I think recognizing our sector, the community-controlled sector, as actually being the pre-eminent provider of Aboriginal health, and that the health workers are the key to that. I think having that recognition, people say those words sometimes, but there's very little demonstration of actually understanding what that means, and actually acting upon that. So, I think that would make a big difference. It would make people who work here feel that they are actually justified in choosing to come here, and actually valued in terms of what they do, truly valued."*
>
> *"We say we couldn't operate without health workers, but we end up talking about hard skills, about their scope of practice, and can they do immunisations, or can't they? But really, most of their value, from a community point of view, is not those things. We can find somebody that can put a needle in someone's arm, but we can't find somebody that actually understands the background of a client and knows why they've come into the clinic so upset, and can actually communicate with them correctly, and in the right way to actually get information they need, to move them forward, to support them. And I think that those "soft skills" shall we call them, are probably the most important things that they provide, but probably the things that we look at least, and value least."*

4. Discussion

We conducted a literature review and subsequent yarns with AHWs and their supervisors at three Aboriginal PHC services to explore the current functioning of the AHW program in NSW. Our co-designed methodology was founded on First Nations research methods and satisfied all 14 criteria of the Aboriginal and Torres Strait Islander Quality Appraisal Tool developed by Harfield et al. (43). This enabled us to gain safe insights into the genuine lived experiences of AHWs and their supervisors. Our study is the first in NSW to directly gather the perspectives of AHWs regarding each key component of the AHW program, as defined by the CHWAIM. The CHWAIM has been validated as an assessment tool by international studies of CHW programs (33, 35). Applying it in our yarns helped establish a holistic understanding of AHW program functioning in NSW.

4.1. Changes for sustainability

The facilitators and challenges that arose from the yarns suggested five broad categories of change that are required in the creation of a sustainable workforce (Figure 5).

Community connection is central to AHW practice. The potential to create a positive community impact is vital both in attracting candidates to the AHW role and creating job satisfaction to increase AHW retention. The yarns suggested that an AHW role that is flexible enough to adapt to community needs and a positive ACCHO-community relationship are key to ensuring this connection. This connection should be prioritized even as AHWs advance within the organization.

Recognition of the importance and expertise of AHWs is vital in promoting their work. The education of stakeholders–including community members other health professionals–regarding the value of AHWs in the health system and the challenges of their work was identified to be essential in recognition. Further, the unique skills of AHWs should be acknowledged by expanding clinical practice and decision-making capacities to reflect their expertise.

Adequate workplace support is essential to prevent burnout amongst AHWs. Our yarns identified that such support should be holistic, encompassing academic, financial and wellbeing supports. Regular, open pathways for communication need to be prioritized and the importance of cultural supervision by senior AHWs should be recognized. Furthermore, value for the work of AHWs must be demonstrated through commensurate pay that is sufficiently competitive to ensure retention. Non-financial incentives such as opportunities for advancement and training opportunities should be

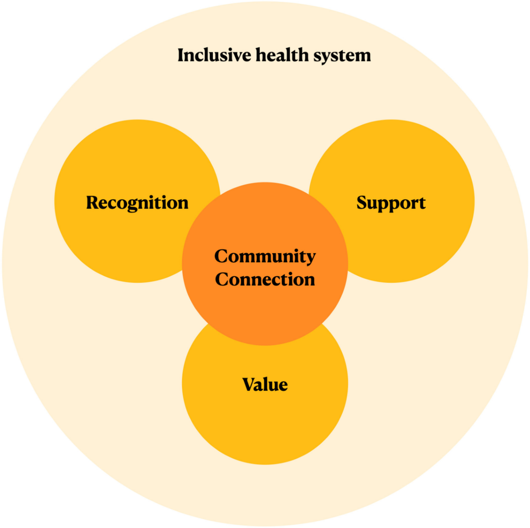

FIGURE 5
Five categories of change to ensure AHW sustainability. This figure summarizes the five categories of change for AHW sustainability emphasized by our yarns, with "Community Connection" central, and an 'Inclusive health system' overarching.

sustainably funded and their requirements clearly articulated so that they are accessible to all AHWs.

All these changes need to be made within a healthcare system that is inclusive of holistic approaches to healthcare such as First Nations understandings of health. Policy changes are required to shift focus from billable clinical services to enable sustainable, complete funding for holistic care providers such as ACCHOs and their AHWs.

These actions are summarized in Figure 6.

4.2. Implications of the five categories of change

The centrality of community connection to AHW practice is emphasized in existing literature on AHWs (8, 25, 44–46). In a mainstream health system, most healthcare positions are defined solely by what they do, or their role "responsibilities". However, following yarning sessions with AHWs across Queensland, Topp et al. identified that beyond any role "responsibility", community-centeredness forms a defining role "orientation" for AHWs.

Peiris et al. explain this orientation using the concept of *kanyini*—a term used by language groups across Central Australia(46). *Kanyini* is derived from an expression describing how a small child is held in one's arm against the breast (*kanyirnu yampungka*) (47). It is "the principle and primacy of caring for others–an obligation to nurture, protect and care for other people, family, and country" (46), and forms one of the four foundations of Aboriginal life, along with *Tjukurpa* (Law, Dreaming), *Walytja* (Family), and *Ngurra* (Land, Country) (47). *Kanyini,* with its notion of "holding", is the foundation that motivates both AHW practice and the care provided to First Nations communities by ACCHOs. Any policy action involving AHWs must acknowledge and prioritize this foundation. The yarns suggested that community orientation could be supported through a role that is adequately flexible to adapt to the needs of the community. This has been echoed by Harris and Robinson following a study of AHWs in a mental health program in the Northern Territory (29). However, biomedical health systems such as Australia's are built on workforce plans which encourage specialization and focus on role responsibilities to create an "optimum skill mix" (9, 48). It is difficult to account for a highly flexible position, let alone its role orientation, in such a system. Indeed, Harris & Robinson found that the AHW role was only able to be "informally" incorporated into existing clinic structures, with non-pharmacological elements of care excluded in planning (29).

This aforementioned inability to fully account for AHWs within the NSW health system is at the center of their sustainability issues. For instance, our second category of change: the need for AHWs to gain recognition for their work, has already been highlighted by existing studies (49–53). An international review exploring First Nations health worker retention identified that recognition encompassed firstly, being entrusted to perform meaningful tasks, and secondly, feeling "seen" for having done so (52). Participants in our study suggested that expanding the AHW scope of practice to entrust more clinical and decision-making responsibilities will help improve recognition. Indeed, this will enable the recognition of AHW expertise by entrusting tasks that are considered "meaningful" within a biomedical model of health. However, it will still fail to gain recognition for the non-clinical expertise of AHWs–expertise which is most important in fulfilling their community orientation, but considered less "meaningful" within mainstream healthcare. The education of professionals, policymakers, and community members regarding the importance of the work of AHWs, as suggested by this study and others (7, 15, 26, 27), may help shift this paradigm. However, such change will require long-term, system-wide effort (15, 54).

The failure to recognize the holistic work of AHWs subsequently impedes the demonstration of value for their work. Each yarn in this study highlighted the importance of commensurate, competitive pay in attracting and retaining AHWs. This has been echoed in many other surveys of AHWs and stakeholders (50, 52, 55, 56). Presently, the AHW salary is fixed by a Commonwealth award (57). It is amongst the lowest of all staff salaries in the NSW health system (57, 58). Our yarns highlighted that ACCHOs may act to demonstrate value for their AHWs by negotiating salaries above the award and providing incentives such as training opportunities. However, ACCHOs in NSW are only partially funded, forcing them to rely on indefinite grants and block funding to finance these opportunities (24). Consequently, even service-level demonstrations of value are vulnerable to funding changes and are typically impermanent (24).

Ultimately, it is clear that to facilitate community connection, recognition, and value for AHWs, the health system must shift to become more inclusive of non-mainstream approaches to health. This will require policy change to implement workforce plans, funding models, and governance structures that are inclusive of non-clinical work and which center Aboriginal Ways of Knowing, Being, and Doing (24, 41). Recent strategies published by state and federal health bodies in Australia emphasize the importance of the AHW role in achieving health parity for First Nations peoples (18, 57). However, they rarely articulate firm commitments to better support the work of AHWs and ACCHOs. Further, many are written without the input of First Nations peoples—a characteristic shown to consistently contribute to policy failure (46).

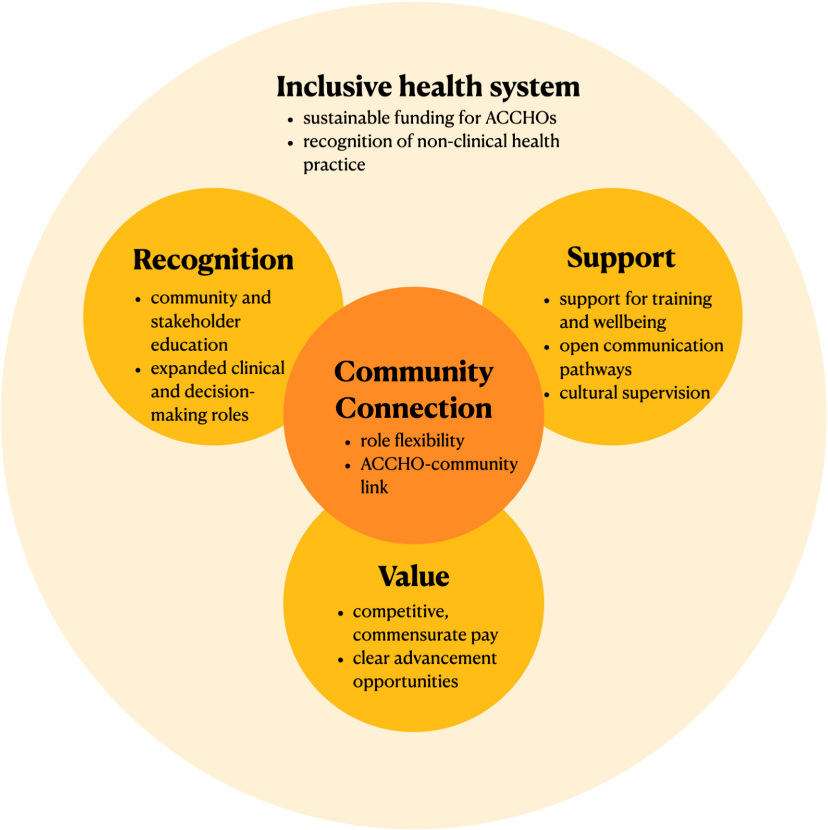

FIGURE 6
Actions to ensure AHW sustainability. This figure summarizes changes suggested by our yarns to potentially improve AHW sustainability within each of the five categories of change. AHW, Aboriginal Health Worker; ACCHO, Aboriginal Community Controlled Health Organisation.

The 2020 "National Agreement on Closing the Gap" (59) is a notable exception to this trend. The strategy, which has been co-designed by Australian governments and Aboriginal and Torres Strait Islander peak bodies, mandates that federal and state governments establish a "Community-Controlled Health Sector Strengthening Plan" by the conclusion of 2021(59). It is hoped that these plans will implement numerous strengths-based changes to build a more inclusive system for AHWs and ACCHOs.

In the absence of such system-wide change, our study suggests that AHW sustainability can continue to be promoted at a service level by focussing on the final category for change: support. A supportive workplace is recognized as vital to the retention of First Nations health workers (8, 60). Cultural support has been identified to be particularly paramount (8). Our yarns highlighted that AHW safety can be promoted by implementing pathways which ensure regular access to cultural supervision, such as regular Aboriginal and Torres Strait Islander staff meetings. Further, participants in our study recognized that professional support for AHWs was impeded by a lack of open communication between AHWs and management. This has been echoed elsewhere (60, 61). Implementing a "partnership model" in which regular opportunities for communication, group problem-solving, and interaction between staff are prioritized has been shown to effectively address these concerns and improve care for First Nations communities (26, 28).

4.3. Strengths and limitations

Overall, our study provides a comprehensive framework of factors affecting AHW sustainability in NSW. This framework can be used to guide service and system-level action to improve the AHW program. Our study also presents a replicable method that can be used to co-design culturally safe AHW studies across Australia. The core strength of our study was its use of Indigenous methodologies that centered on First Nations voices and knowledges. Additionally, despite the competing demands of the COVID-19 vaccination rollout, our study received a high response rate. All three sites willingly participated in the study, and 13 of the 21 employed AHWs participated in the yarning. The final sample of AHWs that participated in the yarn was representative of the diverse roles and backgrounds of staff across the sites, which aided the validity of our results.

Due to COVID-19 travel restrictions, the research team was unable to travel to the ACCHO sites to facilitate in-person yarns. This impeded "social yarning", particularly in the initial yarns at each site. Bessarab and Ng'andu identified that social yarning is vital to building trust, accountability, and group rapport (36), and these links were delayed in our online yarns. Future online studies may account for this by dedicating extra time in initial sessions specifically for social yarning.

One limitation of our study was a small sample size. We collaborated with three regional centers. Given the highly variable nature of AHW practice and the distribution of ACCHOs across remote, regional, and metropolitan areas, these results are not generalisable to the entire AHW workforce in NSW. Co-designing a similar study with more ACCHOs across NSW will help identify specific actions to improve the AHW program and will help inform a more nuanced understanding of the systemic issues facing the NSW AHW program.

4.4. Conclusions

Yarns with AHWs and their supervisors working in PHC in NSW revealed five categories of change that are required to ensure AHW sustainability: community connection, recognition, value, support, and an inclusive health system. There are practical actions in each of these categories that can support AHW retention, such as implementing pathways for regular communication. However, it is evident that a system-wide paradigm shift in healthcare is necessary to truly ensure sustainability. The holistic work of AHWs and ACCHOs must be recognized through workforce plans, funding models and governance structures that incorporate Aboriginal Ways of Knowing, Being, and Doing. Co-designing similar studies with more ACCHOs across NSW can help inform this change.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by UNSW Human Research Ethics Committee (reference: HC210247) Aboriginal Health and Medical Research Council Human Research Ethics Committee (reference: 1800/21). The patients/participants provided their written informed consent to participate in this study.

Author contributions

RJe conducted an initial literature review, coded the interview transcripts for analysis, and synthesized findings to draft this manuscript. RJo developed the original idea for the study in conjunction with BP and JC. JC established contact with potential Aboriginal health services across NSW to co-design the study, co-ordinated an Aboriginal Reference Group, and reviewed the study design and methods to ensure cultural safety. RJo created the yarning guide used in this study and provided a major contribution to the writing and analysis process. BP led the design of the thematic analysis process and also provided a major contribution to the analysis and writing of this study. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.1010301/full#supplementary-material

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EDITED BY
Sunjoo Kang,
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*CORRESPONDENCE
Whenayon Simeon Ajisegiri
✉ wajisegiri@georgeinstitute.org.au

†These authors have contributed equally to this work and share senior authorship

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"We just have to help": Community health workers' informal task-shifting and task-sharing practices for hypertension and diabetes care in Nigeria

Whenayon Simeon Ajisegiri[1]*, Seye Abimbola[1,2], Azeb Gebresilassie Tesema[1,3], Olumuyiwa O. Odusanya[4], David Peiris[1]† and Rohina Joshi[5,6]†

[1]The George Institute for Global Health, University of New South Wales (UNSW), Sydney, NSW, Australia, [2]School of Public Health, University of Sydney, Sydney, NSW, Australia, [3]School of Public Health, Mekelle University, Mekelle, Ethiopia, [4]Department of Community Health and Primary Health Care, Lagos State University College of Medicine, Ikeja, Nigeria, [5]School of Population Health, University of New South Wales (UNSW), Sydney, NSW, Australia, [6]The George Institute for Global Health, New Delhi, India

Introduction: Nigeria's skilled health professional health workforce density is insufficient to achieve its national targets for non-communicable diseases (NCD) which include 25% reduction in the prevalence of diabetes and hypertension, particularly at the primary health care (PHC) level. This places a great demand on community health workers (CHWs) who constitute the majority of PHC workers. Traditionally, CHWs are mainly involved in infectious diseases programmes, and maternal and child health services. Their involvement with prevention and control of NCDs has been minimal. With government prioritization of PHC for combating the rising NCD burden, strengthening CHWs' skills and competencies for NCD care delivery is crucial.

Methods: We conducted a mixed methods study to explore the roles and practices of CHWs in the delivery of hypertension and diabetes care at PHC facilities in four states (two each in northern and southern regions) in Nigeria. We reviewed the National Standing Orders that guide CHWs' practices at the PHC facilities and administered a survey to 76 CHWs and conducted 13 focus groups (90 participants), and in-depth individual interviews with 13 CHWs and 7 other local and state government stakeholders.

Results: Overall, we found that despite capacity constraints, CHWs frequently delivered services beyond the scope of practice stipulated in the National Standing Orders. Such informal task-shifting practices were primarily motivated by a need to serve the community.

Discussion: While these practices may partially support health system functions and address unmet need, they may also lead to variable care quality and safety. Several factors could mitigate these adverse impacts and strengthen CHW roles in the health system. These include a stronger enabling policy environment to support NCD task-sharing, investment in continuous capacity building for CHWs, improved guidelines that can be implemented at the point of care, and improved coordination processes between PHC and higher-level facilities.

KEYWORDS

community health workers, primary health care, service delivery, hypertension, diabetes, non-communicable diseases, skills

Introduction

Most countries have a critical shortage of skilled health workers, in particular doctors and nurses (1, 2). The World Health Organization (WHO) recommends a skilled health professional density of at least 4.45/1,000 population to achieve the sustainable development goals (SDGs) (3). The majority of countries in Africa have densities <2.28/1,000 population (4). Despite having one of the largest health workforces on the continent, Nigeria's skilled health workforce density is only 1.95/1,000 population, well below the recommended benchmark (5). Health system weaknesses due to inadequate number and skills of health workers is most pronounced at the primary health care (PHC) level in Nigeria. These weaknesses threaten the achievement of Universal Health Coverage and national NCD targets which includes about 25% reduction in the premature death from NCDs, prevalence of diabetes, hypertension and obesity (6);—and the ability to address the growing burden of non-communicable diseases (NCDs) in Nigeria.

The deployment of community health workers CHWs to deliver essential health services has proven to be a well-established strategy to address critical skilled health workforce (7, 8). The term CHW is a broad category comprising and although there are over 30 designations different types of health cadres globally, they share the common role of working at the frontline in community (9). The WHO considers CHWs to be members of the community with varying levels of formal education who are trained to address the health problems of individuals and the community (10). They usually share similar life experiences, socio-economic status and ethnicity with the communities they serve (11). CHWs often form the backbone of most health systems (11) at the PHC level and provide a linkage between communities and health systems (12).

The diversity in CHW roles is driven by a wide variation in the duration, content, and level of their training. While some CHWs are formally trained according to structured curricula and have a specified duration in government-recognized institutions, others are informally trained with access to variable content and may work in unregulated settings (13). Although CHW is a generic term used in most countries, each country usually has specific terms and scope of practice appropriate for their CHW cadre. For instance, CHWs are called Accredited Social Health Activists and auxiliary nurse midwives in India (14), Health Extension Workers (HEW) in Ethiopia (15), and Family Welfare Assistants or health assistants in Bangladesh (16).

In Nigeria, CHW titles include Community Health Officers (CHOs), Community Health Extension Workers (CHEW) and Junior Community Health Extension Workers (JCHEW) who have received various degrees of training at government-recognized institutions (6). JCHEWs and CHEWs hold Certificates and Diplomas in community health after completing 2- and 3-year training programmes respectively at Schools of Health Technology. CHOs are CHEWs who possess a higher national diploma obtained through an additional 1-year training programme in PHC at a teaching hospital (17).

The roles and responsibilities of CHWs in Nigeria depend on factors that include (but are not limited to) the level of education, type of training received, health care setting, size of population serviced and geographical coverage (18). These roles may be general or specialized (19) and span health promotion, prevention and treatment of diseases as well as management of data (8). The practice of CHWs is regulated by National Standing Orders which are the primary guidelines for CHW training and delivery of services to the community. They typically describe clinical features of common disease conditions and how they should be managed and define the scope of CHW practice under the instruction and supervision of physicians (20). Apart from ensuring normative guidance in the quality of care, adherence to the National Standing Orders also offer legal protection to CHWs in the course of service provision (21, 22).

CHWs have been traditionally involved in programmes that target infectious diseases and maternal and child services. Their involvement in the prevention and control of NCDs is relatively new and tends to be less well-documented (23). Although some studies have assessed the effectiveness of CHWs in the prevention and management of NCDs elsewhere (24, 25), there is a dearth of studies on CHWs' engagement in NCD care in Nigeria. One study on CHW management of hypertension and diabetes identified substantial knowledge gaps in the diagnosis and treatment of these NCDs (26). A pilot study to assess CHW support and self-home blood pressure (BP) monitoring found that such CHW support had potential to be successfully implemented in PHC settings in Nigeria (27). A study that explored stakeholders' perspectives on the adaptation of a hypertension treatment program for PHC facilities in Nigeria suggested empowering CHWs through training to participate in team-based care was a major enabler to hypertension treatment in those facilities (28).

Given the current knowledge gaps and the central role played by CHWs in the PHC workforce, an assessment of their skills and competencies for carrying out NCD-related activities is crucial to develop and implement NCD policies and programmes in Nigeria. Because the National Standing Orders do not address service delivery for cancers and chronic respiratory illnesses, we focused on hypertension and diabetes care. Study aims were to: (1) describe the role of CHWs in the prevention and control hypertension and diabetes in PHC facilities in Nigeria; (2) identify the policies and practice gaps by comparing CHWs' actual practices with those stipulated in their guidelines; and (3) highlight opportunities for enhancing CHW support to address those gaps.

Methods

We conducted a cross-sectional study with mixed methods data collection approach that included the following: (1) analysis of policies and guidelines related to CHW practices for hypertension and diabetes service delivery; (2) a cross-sectional survey of CHWs to quantify actual NCD service delivery practices; and (3) key informant interviews (KII) and focus group discussions (FGDs) with CHWs and other stakeholders to understand the processes involved in the reported practices in the survey.

Study setting

The study was conducted in 13 PHC facilities across four states in Nigeria (two states in each of the northern and southern regions) between July and September 2019. The PHC facilities were purposively selected to obtain a diverse sample based on available human resources and health-seeking behaviors across the northern

BOX 1 CHWAIM survey domains.

i. **Role and recruitment:** How are CHWs recruited and how are their roles defined?
ii. **Training:** What pre-service and in-service training is provided to CHWs to provide quality care and how are they evaluated?
iii. **Accreditation**: How is knowledge assessed and accredited during pre-service and in-service?
iv. **Equipment and supplies**: What is the availability and access to the required equipment?
v. **Supervision**: How is supportive supervision conducted?
vi. **Incentives**: How are CHWs incentivized/remunerated (both financial and non-financial incentives)?
vii. **Community involvement**: What is the level of community involvement in the CHWs' programmes?
viii. **Opportunity for advancement**: Is career progression an option available to the CHWs?
ix. **Data**: How does data flow from and to the community?
x. **Linkages to the national health system**: What policies are in place that integrate and include CHWs in health system planning, budget, and logistical support?

and southern regions of the country. This resulted in three PHCs selected per state except in one state where four PHCs were selected.

Data collection

We started by reviewing and summarizing the National Standing Orders for hypertension and diabetes control for JCHEWs, CHOs and CHEWs, and PHC guidelines in Nigeria (21, 22, 29).

An interviewer-administered survey was used for obtaining information from CHWs on their socio-demographic characteristics and service provision (overall and specific to NCD-related activities). The survey included elements adapted from the WHO Package of Essential NCDs (WHO PEN) intervention (30) and the United States Agency for International Development Community Health Workers Assessment and Improvement Matrix (CHWAIM) toolkit (31) (Supplementary Appendix 1). CHWAIM was developed in 2011 to help government and non-governmental organizations assess, improve and plan CHW programmes and address implementation gaps. Although it has a maternal, newborn and child health and infectious diseases focus, it is designed to be adaptable for other services (31). In 2018, the Programme Functionality Matrix of the CHWAIM toolkit was reviewed and updated through a systematic review and extensive stakeholder consultation, resulting in ten criteria (32). We adapted these ten criteria or domains to understand the role of CHWs in their workplace, particularly in providing NCD care (Box 1).

We then used findings from the survey to develop CHW interview guides. All three cadres of CHWs across 13 PHC facilities were invited to participate (JCHEWs, CHEWs, and CHOs). Sampling of CHWs for interview participation was not stratified by category, rather an invitation was sent out to all CHWs. FGDs were conducted at each PHC facility, and KIIs were conducted with the head or most senior CHW in a facility. We also interviewed state and local governments stakeholders to understand their perspectives on CHWs' NCD-related work in PHC facilities. These stakeholders supervised CHWs and are involved with disease control (including NCDs) activities at the state and local government levels. Interviews were conducted by the lead author (WSA), who has worked with the Nigerian government at national and frontline level of the country's health system. He was supported by two other trained data collectors. Each FGD involved 5–10 participants, lasting 45–75 min. Each KII lasted 30–45 min. The interviews (KII and IDIs) and FGDs were conducted in English language, digitally recorded and transcribed verbatim.

Data analysis

Survey responses were tabulated using Microsoft Excel. Descriptive variables were illustrated as frequencies and proportions. Qualitative data were coded in NVivo Pro 12. Initial themes were guided by the survey findings and focused on understanding the gaps between policy, guidelines and practice. The research team met regularly to analyses and interpret the themes emerging from the interviews. These meetings helped to refine themes, make appropriate inferences and synthesize findings across study sites.

Ethical considerations

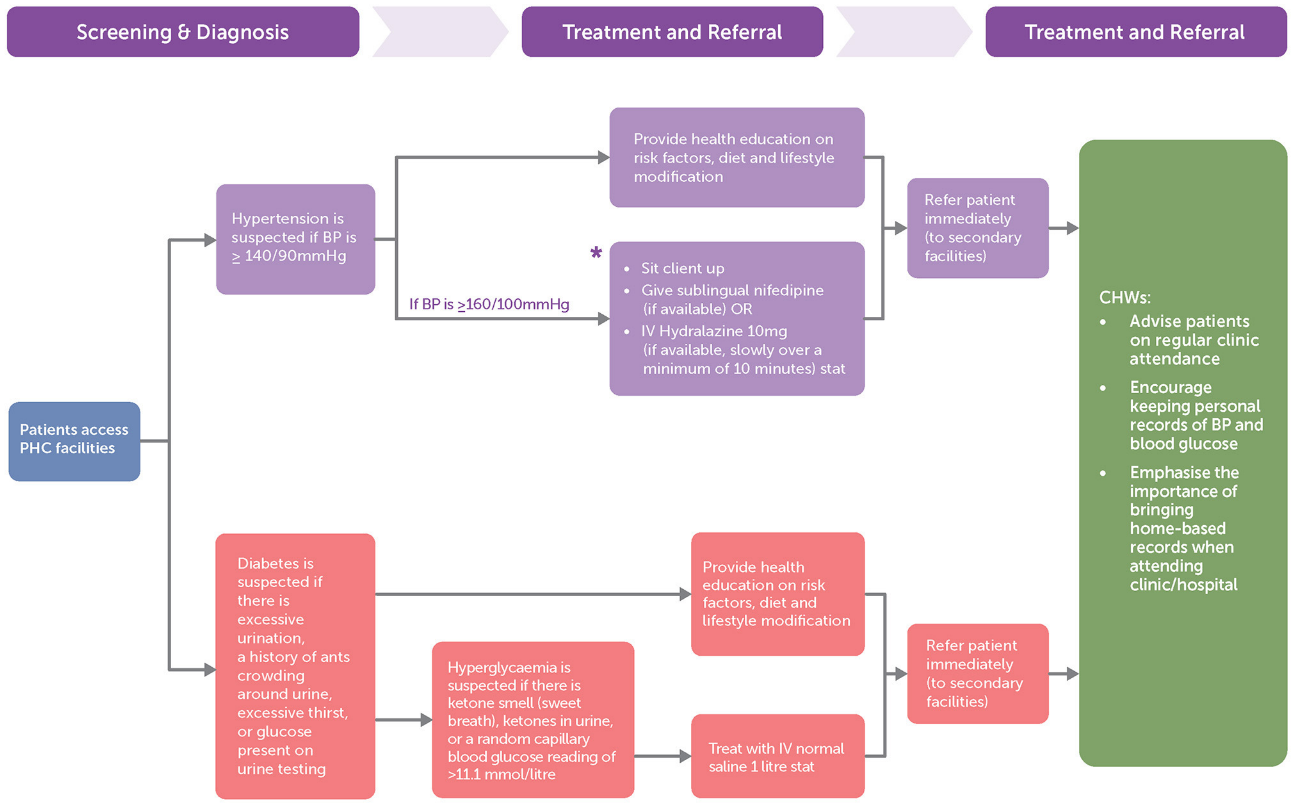
Ethical approval was granted by the National Health Research Ethics Committee of Nigeria (Approval no: NHREC/01/01/2007) and the University of New South Wales Human Research Ethics Committee (HC: 190051). Informed written consent was obtained from all participants that contributed data to the study. Anonymity and confidentiality of all respondents was maintained throughout, and participants names were replaced with codes during data analysis and reporting.

Results

Figure 1 summarizes the National Standing Orders care pathways for CHWs in the delivery of care for hypertension and diabetes at PHC facilities. Management guidance is focused on acute care for people presenting either with elevated blood pressure or symptoms that may be associated with diabetes. There is minimal focus on preventive activities or ongoing chronic care once a diagnosis of hypertension or diabetes is made. This includes limited guidance on: (1) preventive screening of risk factors for diabetes or hypertension; (2) ongoing risk factor monitoring for prevention of complications in patients with established diabetes or hypertension, (3) assessment of cardiovascular disease risks by the CHWs; and (4) follow up treatment with feedback from referral centers (to ensure continuity of care).

Survey findings

Among the 77 CHWs (CHO—9, CHEW—53, JCHEW—15) who participated in the survey on NCD care (representing a response rate of 85%), the vast majority were female, [70 (91%)] with a mix of full-time employment [36 (47%)] and volunteer contract [41 (53%)] workers. The majority worked in a facility with at least one nurse,



*** Actions to be performed by CHEWS/ CHOs only**
Key: IV – intravenous; PHC – Primary Health Care; CHWs – Community Health Workers; BP – Blood Pressure

FIGURE 1
Care of patients with hypertension and diabetes according to National Standing Orders for Junior Community Health Extension Workers (JCHEWs), Community Health Extension Workers (CHEWs), and Community Health Officers (CHOs).

however a minority worked with a doctor (Table 1). Although the majority reported receiving supervision in some areas, a substantial proportion reported receiving no supervisory support at all. Despite high levels of job satisfaction, many CHWs reported barriers to remaining in the job, particularly because of remuneration and in adequate administrative and health professional support.

Table 2 illustrates the self-reported services provided by CHWs compared with the in-service training received for conducting such activities. Blood pressure monitoring was the commonest activity conducted (88%) while cancer screening was the least (17%). CHWs engaged in more activities than they were formally trained for (except for awareness-raising activities for tobacco cessation), and the gap between conducting an activity and receiving formal training ranged from 8 to 31%.

CHWs identified inadequate training (84%), inadequate supplies of equipment (81%), poor infrastructure (71%) and inadequate supervision (52%) as the most frequent barriers to delivery of hypertension and diabetes care.

Qualitative findings

In total, 13 FGDs, 13 KII interviews with facility heads and 7 KIIs with other stakeholders were conducted (Table 3).

Three major themes were identified which influence how CHWs provide hypertension and diabetes care. These related to: (1) variable implementation of the National Standing Orders; (2) CHW role expansion and informal task-shifting; and (3) weak referral linkages.

Variable implementation of National Standing Orders

Despite the National Standing Orders being the main guidance for management of hypertension and diabetes, the CHWs interviewed appeared to interpret them in varying ways. For instance, there was a wide interpretation both between and within facilities of what constituted hypertension *"....If it is above normal, like 140/100 [mmHg].." **(KII7)......**, or "...If somebody has, let's say, he has 170/100 [mmHg], or if he has [systolic of] 140 or 150 [mmHg]...."**(FGD9 participants). and** "....when we take their BP, when the BP is high, maybe its 150 over 90 [mmHg]..." **(FGD7 participants.)*** Similarly for assessing diabetes, some CHWs were familiar with some clinical features but there was less familiarity with interpreting blood glucose values and criteria for diagnosing a patient with diabetes *"...because we are meant to understand that [blood sugar] between 3.5 and 5.9 mmol/l is normal, then from this [value] upward is diabetes..."* ***(FGD4 participants).***

TABLE 1 Characteristics of participants (CHWs) ($n = 77$).

Socio-demographic variables	Frequency (proportion) *n* (%)
Age (years)	
≤29	13 (17)
30–39	25 (33)
40–49	32 (42)
50–59	7 (9)
Mean age (SD): 37.5 years (±8.9)	
Sex	
Female	70 (91)
Male	7 (9)
Marital status	
Married	69 (79)
Unmarried	8 (21)
Categories of CHWs	
Community Health Officers	9 (12)
Community Health Extension Workers (CHEWs)	53 (69)
Junior Community Health Extension Workers (JCHEWs)	15 (19)
Employment type	
Full-time	36 (47)
Volunteer/contract	41 (53)
Highest education level	
Basic national diploma	49 64
Higher level national diploma	17 (22)
Bachelor or master's degree	11 (14)
Duration of working as a CHW	
<3 years	5 (7)
3–10 years	38 (49)
>10 years	34 (44)
Nurse and doctor availability at the facility	
≥1 nurse	56 (72)
≥1 doctor	28 (36)
Type of supervision received	
Direct observation of service delivery	61 (79)
Coaching and skills development	53 (69)
Problem solving	56 (73)
Health record review	55 (71)
Equipment supply check	46 (60)
No supervision received at all	12 (16)
CHW satisfaction	
Satisfied overall with being a CHW	70 (91)
Intend to continue working as a CHW in the future	68 (88)
Reasons CHWs may consider leaving their job	
Inadequate salary	46 (60)
Low support from the higher administrative bodies	43 (55)
Not respected or recognized by other health workers	42 (55)
Not respected by the community	22 (29)
Excess workload	18 (23)
Family or personal reasons	31 (40)

Another limitation to implementation of the National Standing Orders was medication and equipment availability. This led to CHWs having to "improvise" to assess blood pressure and blood glucose: "*Under normal circumstances, different sections or units [are] supposed to have all those equipment, but [when] one section has to wait for the other to finish ….. we design a modality … where all patients that come in [check] their vital signs [centrally] before they go to wherever they are going to. So, [because] there is no equipment, we're just improvising*" ***(FGD13 participants).*** This is particularly a problem for blood glucose testing where patients may be charged a fee for testing and not be able to pay, or glucometers are only available for part of the day: "*….. the glucometer is stationed in the lab, and it doesn't run 24 h, so during the night shift, if you have such cases, … you can't help [the patient]. …*" **(FGD4 participants).**

CHW role expansion and informal task-shifting

Although the National Standing Orders recommend that CHWs refer patients suspected or diagnosed with hypertension, many CHWs were comfortable to initiate treatment and provide ongoing medication management: "*…some will have 130/80, or 140/80, we just give..and ask the person to have rest or come back the second day, to recheck. But, if it is more than that, we can give nifedipine or amlodipine. So, those are the drugs that we use to prescribe* ***(KII9).*** Other CHWs would initiate management and then refer if there was a perceived failure to achieve control: "*…Like if a patient comes in with BP <160/100[mmHg], we try to manage between 23 days, if it doesn't come down you have to refer because there might be something ….*" ***(KII4).*** Similar care processes were described for patients with diabetes"*…if the blood sugar is high,….. we may place the patient on daonil [glibenclamide], just for maybe 3 or 5 days. …..Then, and we advise the patient on diet…..*" ***(FGD13 participants)***.

The criteria for initiating and continuing treatment varied across facilities, based on the attending CHW's discretion and medication availability within the PHC facility. One focus group participant referred to "mild" forms of medication to initiate treatment "*.… It is the CHEW that will give the prescription, and in that aspect, we give the mild one, like nifedipine, amlodipine and diuretic.… we don't give the higher one because, you are trying to just initiate the patient……*" ***(FGD1 participants).***

TABLE 2 NCD-related activities carried out by CHWs.

Domain	Activities	Routinely conducted *N* (%) (A)	Received formal training (%) (B)	Gap between conducting activity and training (A–B)%
Registration of basic demographic and clinical data	Register adults with HTN	53 (69)	22 (33)	31
	Register adults with diabetes	38 (49)	23 (30)	19
Screening/early identification of people with NCDs	Organize screening for HTN	37 (48)	21 (27)	21
	Organize screening for diabetes	34 (44)	22 (29)	15
	Organize screening for cancers	13 (17)	5 (7)	10
Increasing community awareness through engagement and mobilization	Community awareness on fruits and vegetable	59 (77)	44 (57)	20
	Community awareness on physical activities	52 (68)	39 (51)	17
	Community awareness on salt intake reduction	50 (65)	36 (47)	18
	Community awareness on tobacco cessation	41 (53)	54 (71)	−18
	Community awareness on weight control	53 (69)	35 (46)	23
Intervention for patients with NCDs	Regular home visits for NCDs patient (to encourage continuity of care)	46 (60)	34 (44)	16
	Follow up to ensure medication adherence	49 (64)	39 (51)	13
	BP measurement to monitor HTN patients	65 (88)	51 (66)	22
	Blood glucose measurement for DM patients	38 (49)	27 (35)	14
	Counseling patients on smoking cessation	51 (66)	33 (43)	23
	Counseling patients on adopting a healthy diet	54 (70)	33 (43)	27
	Counseling patients on weight control	53 (69)	33 (43)	26
Referral system	Counseling and motivation for referral	59 (77)	40 (52)	25
	Mobilizing support from community to effect referral	44 (57)	31 (40)	17
	Effecting referrals for all cases to the next level	55 (71)	37 (48)	23
	Accompanying patients to next level HF	47 (61)	38 (49)	12
	Get feedback and follow up referred patients	53 (69)	38 (49)	20
Essential drugs	Replenishment of essential drugs at the facility	23 (30)	17 (22)	8
	Prescribed drugs for HTN or DM patients	34 (44)	27 (35)	9
	Refill drugs for HTN or DM patients	34 (44)	17 (22)	22

Although CHWs exercise considerable discretion in how they implement the National Standing Orders, by contrast several government stakeholders held more rigid views that their role should be restricted to screening and referral. Many felt that the formal training provided to CHWs in the college of health technology is insufficient for taking on a treatment role: "*….. the reason why they are training them is so that they can recognize (non-communicable diseases) …. if they see anyone with it they can refer…*" ***(KII-Stakeholder).*** Another justification for restricting CHW scope of practice was related to limited medication supply. Although NCD drugs are on the list of essential drugs and should be available at PHC facilities, frequently such medications are not available: "*… since they*

TABLE 3 Interview and survey participants.

Community health workers			
Facility/region	**KII participants**	**FGD participants**	**Survey participants**
PHC facility 1, North	KII1: M, 54 years, CHEW	FGD1: 4 M, 6 F	7
PHC facility 2, North	KII2: F, 40 years, CHO	FGD2: 5 F	4
PHC facility 3, North	KII3: F, 45 years, CHO	FGD3: 3 M, 6 F	5
PHC facility 4, North	KII4: F, 45 years, CHEW	FGD4: 2 M, 6 F	7
PHC facility 5, North	KII5: F, 49 years, CHO	FGD5: 1 M, 5 F	6
PHC facility 6, North	KII6: F, 55 years, CHO	FGD6: 4 M, 6 F	9
PHC facility 7, North	KII7: F, 48, years CHO	FGD7: 2 M, 4 F	6
PHC facility 8, South	KII8: M, 55 years, CHO	FGD8: 4 F, 6 F	7
PHC facility 9, South	KII9: M, 55 years, CHO	FGD9: 3 F, 6 F	6
PHC facility 10, South	KII10: F, 40 years, CHO	FGD10: 10 F	5
PHC facility 11, South	No participant	FGD11: 10 F	4
PHC facility 12, South	KII12: F, 38 years, CHO	FGD12: 8 F	5
PHC facility 13, South	KII13: F, 41 years, CHO	FGD13: 6 F	6
Stakeholders			
Agency/organization	**Designation**		
State ministry of health	KII-S1: male, director of public health		
State primary health development agency	KII-S2: male, director of health planning research and statistics		
	KII-S3: male, director of disease control		
	KII-S4: male, director, community health services and education		
	KII-S5: male, medical officer of health		
	KII-S6: male, medical officer of health		
Community health practitioner registration board of Nigeria/college of health technology	KII-S7: male, senior lecturer		

(CHWs) are not treating it, they don't need to buy...…. there are no drugs for NCDs in the PHC ***(KII- Stakeholder).***

One motivator for extending their scope of practice beyond that stipulated in the National Standing Orders' is the sense of addressing unmet need: *"….. where our "Standing Orders" say you should treat hypertension, most…will say "refer", …(but) by initiating or starting them on medication, … we are just helping…."* ***(FGD1 participants).*** Some government stakeholders felt an expanded scope of practice was needed to maintain patients' trust in the services provided at the PHC facility. Because referring patients to higher level facilities could negatively affect perceptions of PHC level care, participants believed that CHWs had to strike a balance *"…so that it doesn't water down the respect they have for the [PHC] system…. If you refer, the person needs to understand that it's not because of the fact that you are not competent to care … In terms of NCDs also, if we don't manage that aspect carefully, it may also affect patronage…"* ***(KII- Stakeholder).***

Another important motivation was the sense of prestige derived from displaying similar skills to doctors. Some CHWs believed that they've worked long enough with physicians to acquire the experience needed to treat patients: …. *"we have worked longed enough with doctors, so, we also have the experience [to treat hypertension]…* ***(FGD5 participants).****"* This appears to be influenced by gender with one stakeholder commenting that male CHWs functioned like doctors at the PHC facility: *"…in the past, there were no doctors at the PHC system…. Every male you see is "a doctor"… what doctors are doing now, were being handled by CHOs …. they do prescribe anti-hypertensive and anti-diabetics [but] the extent to which they can is something to debate"* ***(KII- Stakeholder).***

Weak referral linkages and non-compliance with referral guidelines

A related barrier to optimal care was the perception that referral processes are inadequate. CHWs use a two-way referral form which is intended to support communication between CHWs at PHC facilities and health workers at secondary health facilities. Implicit in this is the expectation that the secondary facility staff will refer patients back to PHC facilities with clear feedback to aid continuity of care. CHWs commented that this feedback provides a learning opportunity on *"what to do next when there's another patient with a similar case…"* ***(FGD13 participants).*** However, many participants said the feedback from secondary health facilities is often not given or ineffective: *"…. after referring, most of these facilities don't give a response back. We are the only ones that attempt to call the patient to know their well-being."*

(FGD13 participants). The lack of feedback may result in CHWs initiating a new treatment plan at their own discretion*"…since I've been working here, I've not seen any feedback. …. That is why we do make calls to contact the patient…. It's very, very important [to get feedback].. we will know the health of that patient… but since we are not getting feedback, there's nothing we can do…"* ***(KII13).*** As a strategy to overcome the challenges of feedback from secondary facilities, some CHWs employed workarounds such as directly telephoning or visiting secondary health facilities. Unfortunately, such a resource intensive effort such as this would not address the problem: "*We normally go there to collect the feedback ourselves, and sometimes when we go there we do not even get the feedback….they will say the doctor is yet to sign it, the patient will be well, and the feedback is not yet signed* ***(KII6).***

Discussion

This mixed methods study explored practices of CHWs in hypertension and diabetes care in two states in Nigeria. We found that CHWs flexibly implement national guidelines for hypertension and diabetes exercising considerable discretion in interpretation. Further, we identified considerable workforce capacity gaps, system barriers including inadequate medication and equipment supplies, and challenging referral processes characterized by limited communication between PHC facilities and higher-level facilities. The findings suggest the need for a re-appraisal for how NCDs are integrated into PHC care with consideration of the following four areas: (1) formalize task-sharing and task-shifting policies for NCDs among CHWs; (2) enhance the National Standing Orders with simplified NCD clinical algorithms/guidelines that can easily be used by CHWs at the point of care; (3) Provide continuous capacity building for CHWs to enhance their roles in NCD care; and (4) improve care coordination between PHC and higher-level facilities.

Formalize task-sharing and task-shifting policies for NCDs among CHWs

CHWs are central to shifting or sharing tasks traditionally undertaken by skilled health workers (33). Although task shifting models involving CHWs have been successfully implemented in Nigeria for maternal and child health programmes, infectious diseases management and provision of contraceptive implants (34, 35), such models have thus far been overlooked in NCD service delivery. Despite the lack of explicit policies in this area, we found abundant evidence of CHWs informally taking on the roles of physicians. Given the widespread nature of such informal task-sharing care models, it would be short-sighted and impractical to eliminate such practices. Rather, such practices may need to be explicitly endorsed, formalized into policy and supported by the health system—all requiring a substantial shift in what is currently stipulated in guidelines and policies.

In settings where health system pressures from NCDs are growing, task-shifting and task-sharing models of service delivery by non-physicians play a central role (36). There is mounting evidence that such strategies are feasible and cost-effective in LMICs (37, 38). However, this requires considerable strengthening and restructuring of the PHC system as task-shifting functions cannot occur in isolation and wider system reforms are required (38, 39). It requires appropriate remuneration structures, enhanced commitment to capacity building, provision of supportive supervision and active engagement with physicians, development of workforce policies that support team-based care, and the creation of the appropriate environment for its implementation, including addressing complex challenges such as role overlaps between different health worker cadres and community perceptions that might impact demand-side factors. Nigeria has considerable experience in implementing task-shifting structures for HIV and reproductive health and this should be leveraged for including reforms for NCD care (34, 35). In the absence of such reforms, informal practices will remain tacit, of variable quality and with high potential for unsafe care.

Enhance CHW standing orders with simplified NCD clinical algorithm/guidelines that can be used at the point of care

Although the National Standing Orders are intended to guide CHW practices, they lack sufficient clarity to ensure compliance. The structure and volume of the Standing Orders themselves may pose a challenge for adherence and there is a need to have more simplified, unambiguous, NCD-specific clinical algorithms that are easy to use at the point of care. The current National Standing Orders do not include cardiovascular risk assessment as recommended in WHO guidelines. By adopting such an approach, CHWs will have greater guidance on implementation of a total risk approach to care leading to improved identification of people most in need of referral and treatment (30). There is robust evidence that such an approach can be feasibly and effectively implemented in many LMICs (40, 41), especially when the services are being delivered by non-physicians (42). Digital clinical decision support tools have also been shown to support task sharing models for hypertension and diabetes care (43–46). Currently there is little work being undertaken in this area in Nigeria. Such algorithms also need to be accompanied by appropriate and regular supportive supervision and accountability to support their uptake. There is also a need to integrate such supervision into existing training processes for infectious and other diseases rather than establishing separate structures.

Provide continuous capacity building for CHWs

The wide discretion with which CHWs engage in care practices combined with minimal training opportunities was a key study finding. These practices are indications of system weakness and suggest high levels of unmet need that CHWs are attempting to address (47). While CHWs were motivated by multiple factors to act beyond their scope of practice in the delivery of care for NCDs, ensuring a functional PHC facility and the need to provide care for their communities appeared to be the dominant motivations. This sense of duty may be accompanied by an increase in perceived professional status. Some CHWs felt empowered when members of their community viewed them as integral members of the health system (48), comparable to other professionals such as nurses and doctors (49). As CHWs are strongly motivated to strengthen the health system for the communities they serve (50), there are major opportunities to further empower them, commensurate with their desired competencies. This would support them to provide an optimum quality of care and mitigate against feelings of being undervalued or undermined in their communities and facilities of practice. Empowerment of CHWs to strengthen NCD service delivery requires multi-level capacity building at substantially greater degree than what is currently being provided. Such capacity building needs to be implemented in training colleges and then continuously supported with pre-service and regular in-service training (41, 51).

Improve care coordination between PHC and higher-level facilities

To support follow up and long-term monitoring of patients with hypertension and diabetes by CHWs at the PHC facilities, this study identified the need to strengthen the referral and feedback processes and enhance care continuity and quality (52, 53). This can be partly achieved by making simplified referral guidelines available. As seen in this study and others, non-adherence to referral guidelines was common practice among CHWs (54, 55). It is therefore important to implement more effective mechanisms to support adherence to referral guidelines including supportive supervision and continuous CHW training (56). Although these findings are limited to NCDs (in particular hypertension and diabetes management), they are likely to be relevant to other areas of CHW practice.

However, there are also important discrepancies in perceptions of CHW roles, their scope of practice, and the functions of the PHC sectors more broadly that must also be addressed. These discrepancies may represent a deeper issue of how CHW roles and responsibilities are defined in policy, while they themselves do not have significant input into defining their own practice (57). The insights and skills that CHWs might have developed in the course of overcoming challenges in their practice are often not recognized when new policies and initiatives are developed (58). English and colleagues highlight that the tacit and contextual knowledge held by those in practice must be harnessed for implementing successful interventions (59). The omission of frontline worker perspectives could undermine success of health system reforms (60). These issues highlight the need to support PHC teams in which health workers of disparate training levels can work together to deliver accessible, high quality, coordinated care whether that be in PHC or higher-level care facilities (61).

Study limitations

The findings of this study may not hold across all PHC facilities in Nigeria, especially those PHC facilities with physicians fully on staff. However, the majority of the PHC facilities have no or limited physician presence. Another possible limitation of the study is that the findings could be influenced by courtesy bias, particularly given we relied on self-reported data to determine care practices. To minimize these biases, we assured the participants of strict confidentiality and the potential benefits to improving workforce support if the authentic situation was presented. We also were able to triangulate the findings across the quantitative and qualitative data sources. Lastly, our study did not directly explore community and patient perspectives with respect to NCDs care. This could provide a deeper understanding of demand-side barriers to NCD care including perceptions of the role of CHWs, and identify opportunities for greater community engagement to support improved implementation of NCD policies. We recommend that future studies should explore this aspect.

Conclusion

CHWs play key roles at the PHC level in addressing the growing burden of NCDs in Nigeria. However, these roles are at times beyond their allowed scope of practice and greatly limited by access to adequate training and supervision. This could compromise health care quality, raising the need to better equip this workforce for effective NCD service delivery at PHC facilities in Nigeria. Such considerations include formalizing task-sharing and task-shifting policies for NCDs among CHWs and fostering an enabling environment for their implementation; enhancing the National Standing Orders Development with point of care clinical algorithm/guidelines; continuous capacity building during working life; improved care coordination processes between PHC and higher-level facilities; and the promotion of multi-disciplinary team based approaches. Development of new policies in these areas should include substantial engagement with CHWs in their design. CHWs are highly motivated to deliver high quality NCD services and there are major opportunities to better support and leverage this workforce to strengthen Nigeria's health system response to NCDs.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by National Health Research Ethics Committee of Nigeria (Approval no: NHREC/01/01/2007) and University of New South Wales Human Research Ethics Committee (HC: 190051). The patients/participants provided their written informed consent to participate in this study.

Author contributions

The study was conceptualized by WA, RJ, and DP. Data collection was conducted by WA and supported by OO. WA, RJ, OO, DP, and SA were involved analysis of the qualitative data. All authors provided critical intellectual input during the analysis. Manuscript was drafted by WA. All authors reviewed the draft manuscript and approved the final version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1038062/full#supplementary-material

SUPPLEMENTARY APPENDIX 1

CHWs' survey questionnaire.

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Julie Ann St. John,
Texas Tech University Health Sciences Center,
United States

REVIEWED BY
Rahbel Rahman,
Fordham University, United States
Kaston Anderson-Carpenter,
Michigan State University, United States
Kenneth Maes,
Oregon State University, United States

*CORRESPONDENCE
Dulce J. Jiménez
✉ dulce.jimenez@nau.edu

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Community Engagement Alliance (CEAL) Against COVID-19 Disparities: Academic-community partnership to support workforce capacity building among Arizona community health workers

Dulce J. Jiménez[1]*, Omar Gomez[1], Ruby Meraz[2], Amanda M. Pollitt[1], Linnea Evans[1], Naomi Lee[3], Matt Ignacio[4], Katherine Garcia[2], Richard Redondo[2], Floribella Redondo[2], Heather J. Williamson[1], Sabrina Oesterle[4], Sairam Parthasarathy[5] and Samantha Sabo[1]

[1]Center for Health Equity Research, Northern Arizona University, Flagstaff, AZ, United States, [2]Arizona Community Health Workers Association, Douglas, AZ, United States, [3]Department of Chemistry and Biochemistry, Northern Arizona University, Flagstaff, AZ, United States, [4]Southwest Interdisciplinary Research Center, School of Social Work, Arizona State University, Phoenix, AZ, United States, [5]Division of Pulmonary, Allergy, Critical Care and Sleep Medicine, Department of Medicine, University of Arizona, Tucson, AZ, United States

The COVID-19 pandemic has both highlighted and worsened existing health inequities among communities of color and structurally vulnerable populations. Community Health Workers, inclusive of Community Health Representatives (CHW/Rs) have entered the spotlight as essential to COVID-19 prevention and control. To learn about community experiences and perspectives related to COVID-19 and inform CHW/R workforce capacity building efforts, a series of focus groups were conducted with CHW/Rs throughout Arizona at two time points in 2021. Throughout the data collection and analysis process, researchers and community partners engaged in ongoing and open dialogue about what CHW/Rs on the ground were reporting as priority community concerns, needs, and challenges. Thus, CHW/Rs informed the development of culturally and linguistically relevant health education messages, materials, and training for CHW/Rs. In this community case study, we detail the efforts of partnership between a statewide CHW professional association and an academic research team that facilitated rapid decision-making and knowledge sharing to create community-grounded tools and resources supportive of CHW/R workforce capacity building in the context of the COVID-19 pandemic.

KEYWORDS

community health worker (CHW), community health representatives, COVID-19 pandemic, academic-community partnership, mixed methods, Latinx/Hispanic, American Indian/Indigenous

1. Introduction

The COVID-19 pandemic has both highlighted and worsened existing health inequities among communities of color and structurally vulnerable populations (1–3). Various studies have documented racial, ethnic, and socioeconomic disparities in COVID-19 incidence, hospitalizations, and mortality, with African American, Latinx/Hispanic, and American Indian/Alaska Native populations bearing the greatest burden (2–6).

In tandem with the COVID-19 pandemic, the world has also witnessed an infodemic or an excess of rapidly spreading information in both the physical and digital global environments, including the spread of false news and misinformation that have undermined public health efforts in the fight against COVID-19 (7–10). Community health workers (CHWs) – inclusive of tribally employed community health representatives (CHRs) and promotores de salud among other titles – have entered the spotlight as powerful assets in COVID-19 prevention and control, including addressing misinformation (11, 12). CHWs are frontline public health workers who are trusted members of the communities they serve and as such, have a unique understanding, sharing the culture, language, and lived experiences of the clients they serve (13, 14). As valuable members of public health and care teams who are effective in reducing health disparities and improving health outcomes, CHWs play a vital role in addressing medical and social determinants of health (SDoH) among underserved populations (14). As experts who represent and advocate for the communities they serve, CHWs may also help ensure the social validation of goals, procedures, and effects for public health interventions, for example by aligning research goals with community concerns, assessing the acceptability and relevance of study methods, and evaluating the social significance of outcomes (15). Globally, CHWs have been pivotal in pandemic responses, especially in low and middle income countries (12, 16) and are well-positioned to play essential roles in community-based COVID-19 responses now and in the future (11).

CHWs serve as a bridge between community members and fragmented systems of care, and can support efforts to ease fear and correct false information in disadvantaged communities by leveraging their cultural connectedness and shared lived experiences to offer trusted advice and education (17–19). Examples of how CHWs have mobilized during the pandemic include connecting clients to basic services such as food pantries and food distribution sites, rent assistance, primary care providers, and mental health resources; navigating health systems, complex unemployment filing systems, and resources for undocumented immigrants; facilitating delivery of medications; creating and disseminating culturally and linguistically relevant health education materials; and providing social support to isolated older adults *via* phone (17, 18). CHWs have the expertise, connection, and credibility needed to address the overwhelming misinformation around COVID-19 and its potential to have devastating impacts in underserved communities, including rural areas (18, 20). However, the ever-evolving nature of COVID-19 and related public health guidance has made it difficult for both communities and health professionals, including CHWs, to stay updated on the most current and accurate information, highlighting the need for ongoing education efforts.

2. Context

Since the beginning of the pandemic, Arizona has been one of the hardest-hit states in the US, continuously ranked among the highest in case and death rates, at times having the highest rate of new cases in the country (21) and even in the world twice (22). With close to 2 million all time COVID-19 cases, nearly 28,000 deaths (23), and a population of almost 7.3 million (24) policies at the Arizona state level have been insufficient to effectively prevent and control the spread of COVID-19. In light of regular spikes in COVID-19 cases since 2020, Arizona's Governor Doug Ducey routinely denied science based COVID-19 prevention and control measures, including declining to institute a statewide mask mandate, allowing businesses to remain open, and letting school districts make their own decisions about operations (25).

In September of 2020, the National Institutes of Health (NIH) funded the Community Engagement Alliance (CEAL) Against COVID-19 Disparities in 11 of the hardest hit states, including Arizona, to conduct outreach and engagement efforts in ethnic and racial minoritized communities disproportionately affected by the COVID-19 pandemic (26). The Arizona CEAL Consortium (AZ-CEAL) is a collaboration of Northern Arizona University (NAU), University of Arizona (UA), Arizona State University (ASU), Mayo Clinic, and the Arizona Community Health Worker Association (AzCHOW). In partnership with members and leaders of African American, Hispanic/Latinx, and American Indian communities, the Arizona CEAL aims to provide trustworthy information through active community engagement and outreach to the people hardest-hit by the COVID-19 pandemic, with the goal of building long-lasting partnerships as well as improving diversity and inclusion in our research response to COVID-19. Specifically, the purpose of AZ-CEAL is to:

1. Conduct community-engaged research and outreach to assess awareness, experiences, concerns, attitudes, needs, knowledge, and misconceptions regarding COVID-19 testing, prevention, research participation, vaccination uptake, and medical mistrust.
2. Develop culturally-appropriate dissemination materials and strategies designed to educate about COVID-19 infection, transmission prevention, testing, and vaccination; decrease misinformation; and increase medical trust.
3. Implement and evaluate the dissemination of materials and educational strategies on enhancing awareness, trust, willingness, ability, self-efficacy, and participation, of underserved communities in advancing the prevention and treatment of COVID-19.

This paper focuses on NAU's Center for Health Equity Research (CHER) equitable partnership with AzCHOW, an Arizona organization of community-based advocates that has been advocating for the work of CHW/Rs in the state since 2001. AzCHOW builds CHW/R capacity across disciplines to address CHW workforce policy and sustainability issues while serving Arizona's underserved and at-risk populations. By way of resource sharing, partnership development, education, outreach, health promotion, and disease prevention strategies, AzCHOW works toward improving the health of Arizona residents (27). NAU and AzCHOW collaborated to develop and disseminate accurate, up-to-date COVID-19 information for CHWs to take back to their communities.

Previous work highlights the importance of engaging CHW professional associations and CHWs in the research process, including substantive pieces such as designing the study, collecting, analyzing, and interpreting data, and disseminating findings (28, 29). Following best practices in community-engaged research, NAU and AzCHOW partnered equally and intentionally involved CHWs throughout the research process and resulting CHW capacity building training. This collaboration between researchers, a CHW professional association, and

CHWs facilitated targeted and methodologically sound research by ensuring effective and relevant study design, recruitment and participation, and action following research findings (28, 29).

In Arizona, the CHW workforce is estimated at 1500–2000 CHWs employed in county and tribal health departments, health centers, schools, churches, and not-for-profits. Furthermore, the CHR workforce, comprised of tribally employed CHWs, is the oldest and only federally funded CHW workforce in the United States, consisting of a highly trained, well established standardized workforce serving the medical and social needs of American Indian communities (30). Since both CHWs and tribally employed CHRs were engaged in this study, we will use the title CHW/R.

As frontline responders who are also members of the communities they serve, CHW/Rs have a unique understanding of their community's experiences during the COVID-19 pandemic. To learn about community experiences and perspectives related to COVID-19 and inform CHW/R workforce capacity building efforts lead by AzCHOW, a series of focus groups were conducted with CHW/Rs throughout the state. Focus group conversations with CHW/Rs happened at two time points in 2021 and were aimed at exploring CHW/R client experiences and perspectives related to COVID-19 and CHW/R experiences, strategies to overcome challenges, and professional training priorities during the pandemic. The information shared during focus groups was used to develop and adapt COVID-19 educational materials and health education messages, and to identify knowledge gaps and training priorities for CHW/Rs. In this community case study, we detail the efforts of partnership between a statewide professional association (AzCHOW) and an academic research team (NAU) that facilitated timely data collection and analysis for rapid decision-making and action to support the Arizona CHW workforce during the COVID-19 pandemic.

3. Key programmatic elements

3.1. Survey and focus groups

We employed a highly participatory research approach that included AzCHOW staff and CHW/Rs in all phases of the work, from study design to data collection and dissemination. To learn about CHW/R client challenges, needs, and misinformation related to COVID-19 as well as CHW/R experiences, strategies to address COVID-19 challenges, and their training priorities, we conducted focus groups with volunteer and employed CHW/Rs at two distinct time points during the COVID-19 pandemic. The focus group guide was designed for semi-structured discussion and included questions such as, "What types of misinformation or myths have your clients shared with you about COVID-19 that you know or believe is not true and how are you correcting these myths?" and "What are the priority training topics and tools that you want and need to support your clients?" Qualitative research methods were adapted over time to meet the rapidly shifting context of the pandemic and address the urgent education and communication needs of the CHW/R workforce and their clients. Prior to conducting phase 1 and 2 focus groups, research staff conducted two pilot focus groups in English and Spanish in December 2020 to test the focus group guide tool with CHW/Rs.

3.1.1. Recruitment

CHW/Rs were recruited using purposive sampling primarily through AzCHOW's email listserv, which includes approximately 460 email addresses for CHW/Rs, CHW/R supervisors, and partners. Recruitment also happened through word of mouth from CHW/R colleagues and research staff. A total of $N = 54$ participants took part in focus group sessions during the two phases. Of the 54 CHW/Rs, 8 participated in both phase 1 and phase 2 focus groups, leading to a total of $N = 46$ unique Arizona CHW/Rs. To reach tribally employed CHW/Rs serving American Indian populations living on tribal lands, we obtained human subjects research approval from three tribes and recruited CHW/Rs employed by the program using flyers shared *via* the CHR supervisor. Tribes will remain anonymous as per tribal approval agreements. All procedures for this study were approved by the University of Arizona Institutional Review Board (Protocol # 2011244240).

3.1.2. Data collection and analysis

Before participating in the focus groups, CHW/Rs completed a brief online survey *via* Qualtrics. The online survey assessed CHW/R demographics (i.e., race/ethnicity, age, gender, education, and employment), COVID-19 prevention behavior (i.e., frequency of mask use, hand washing, and social distancing), likelihood to get the COVID-19 vaccine, and trusted sources of COVID-19 information.

3.1.2.1. Phase 1

The first set of focus groups ($N = 10$ sessions) were conducted between January–March 2021. At the beginning of February 2021, Arizona had 762,593 total COVID cases (31), 13,124 total deaths (31) and had administered 883,808 doses of the COVID-19 vaccine with only a fraction of all eligible Arizonans fully vaccinated (2.2%, $N = 147{,}595$ for population age 5 years or older) (32).

This initial phase consisted of 10 focus groups, where 30 Hispanic/Latinx CHWs participated in 7 focus groups and 11 American Indian CHRs participated in 3 additional focus groups ($N = 41$ total participants employed across the state of Arizona). Focus groups were conducted virtually through Zoom by bilingual, bicultural research staff representative of Latinx and Indigenous lived experiences, in the English and Spanish language. Conversations lasted 90 min and were audio recorded and transcribed verbatim by research staff. Audio and transcript files were then reviewed, and a code book was developed from the data. Four research staff independently coded the transcripts in ATLAS.ti 8 and identified common themes for each focus groups conversation topic through a process of consensus.

3.1.2.2. Phase 2

The second set of focus groups ($N = 4$ sessions) were conducted in August 2021. At the beginning of August 2021, Arizona had 929,541 total COVID cases (31), 18,251 total deaths (31), and had administered 7,636,771 doses of the COVID-19 vaccines with just over half of all eligible Arizonans fully vaccinated (50.9%, $N = 3{,}438{,}112$ for population age 5 years or older) (32) .

This second phase consisted of 4 focus groups, where 8 Hispanic/Latinx CHWs participated for a second time in 2 focus groups and 5 new American Indian CHRs participated in 2 additional focus groups ($N = 13$ total participants employed across the state of Arizona). At this phase, and to allow for rapid planning and action among decision-makers involved in the COVID-19 response, a rapid assessment procedure (RAP) was used to collect and analyze phase 2 focus group data. The RAP tool was adapted based on real-time evaluation, iterative methodology (33), and rapid appraisal methods (34) to guide the focus group data collection, analysis, and output to enhance decision-making. The tool comprised a field annotation template of pre-defined constructs developed using the focus group conversation guide questions. Detailed field notes were made by three to four trained research staff during the focus groups using the template to generate focused results. Field annotation notes were summarized, and salient themes were identified through consensus among the entire NAU-AzCHOW team.

All phases of analysis and interpretation were conducted in collaboration with the AzCHOW team representative of CHWs and CHRs.

3.1.3. CHW/R participant demographics

Table 1 summarizes demographic characteristics and Table 2 describes likelihood to get vaccinated for COVID-19, COVID-19 prevention behaviors, and trusted sources of COVID-19 information for the 46 unique CHW/Rs that participated in the focus groups across the two phases.

Across the two phases, CHW/R participants predominantly identified as women (89.1%, $N = 41$), having completed a minimum of a high school or GED education (93.5%, $N = 43$), and a balanced range in age with half being between 25 and 40 years old and the other half 41 and older. About three-quarters of CHW/Rs were Hispanic of any race (73.9%, $N = 34$) including three (6.5%) who were Hispanic American Indian CHW/Rs, and the remainder identified as non-Hispanic American Indian (23.9%, $N = 11$) and one (2.2%) non-Hispanic white participant. See Table 1.

CHW/R participants in both phases largely engaged in COVID-19 primary prevention behaviors, with 95.7% ($N = 44$) reporting wearing masks very often or all of the time, 100% ($N = 46$) washing their hands very often or all of the time ($N = 46$, 100%), and 100% ($N = 46$) practicing social distancing at least sometimes. The majority of CHW/R participants reported that they were very likely to get the COVID-19 vaccine (80.4%, $N = 37$) months before the vaccines were widely available. The top three sources CHW/Rs trusted the most to provide correct information about COVID-19 were their own doctors or health care providers (73.9%, $N = 34$), the U.S. Coronavirus Task Force (43.5%, $N = 20$), and their faith leaders (34.8%, $N = 16$). The least trusted source was their own contacts on social media, with 54.4% ($N = 25$) of CHW/Rs reporting trusting them "not at all". Approximately half to two thirds of CHW/Rs reported trusting the remaining sources "a little" (i.e., close friends or family; people they work with, classmates, or others they know; news on the radio, TV, online, or in newspapers; US government; Arizona state government; local tribal government; and neighboring tribal government) see Table 2.

3.1.4. CHW/R-identified priority training topics

CHW/R participants identified priority training areas based on their client's challenges and needs. The most salient priority area among both CHWs serving Latinx communities and CHRs serving AI communities was COVID-19 vaccines, including topics such as vaccine contents, safety and side effects, efficacy, and benefits. COVID-19 information was rapidly evolving, sometimes changing from 1 day to the next, and CHW/Rs needed accurate and up to date information on the COVID-19 vaccines to support them answer their client's questions, respond to their concerns, address misinformation, and help them make informed decisions about vaccination.

TABLE 1 Community health worker/representative ($N = 46$) demographics – combined phases 1 and 2.

Variable	Percent (Frequency)
Age ($N = 28$)	
25–40	50.0% (14)
41–50	21.4% (6)
50+	28.6% (8)
Race/Ethnicity	
Hispanic, any race including American Indian	73.9% (34)
Non-Hispanic American Indian	23.9% (11)
Non-Hispanic White	2.2% (1)
Gender Identity	
Woman	89.1% (41)
Man	10.9% (5)
Education	
High school or GED	43.5% (20)
Associate's or technical degree	41.3% (19)
Bachelor's degree	8.7% (4)
Prefer not to answer	6.5% (3)

> "Many may ask "what's the difference between Pfizer and Moderna?" What is the difference? [...] just give me the nitty gritty. The current, what does it contain, what are the side effects, if any? Give me the worst case scenario and then tell me the positives, so I can promote that it is a good thing."

> "For me, it would be just having a basic understanding on how the vaccine works, because I had somebody asked me how effective it was, and I wasn't sure how to answer that because there's two vaccines right now that are out and they're different. I just don't know the difference between them. So, for me, it would be knowing exactly how it works and being able to relay that in a way."

Another priority training area for CHW/R participants was mental health, including topics of anxiety and depression, isolation, grief, and loss. Again, both Latinx-serving CHWs and AI-serving CHRs expressed the importance of mental health resources to support their clients as well as their own mental wellbeing during the pandemic. During the COVID-19 pandemic, CHW/Rs faced mental health challenges in their work and the highlighted the need for appropriate self-care training for themselves and their clients. Due to the nature of their work, CHW/Rs were exposed to health risks related to COVID-19 as well as mental health risks in navigating emotionally difficult situations with their clients. The emotional toll of working with grieving clients who lost family and friends was not new, but the pandemic highlighted these experiences and exposed the need for self-care techniques and mental health resources.

> "PTSD could be something from COVID just especially with people who lost loved ones, grieving processes, that'd be something, a training that would be good to work with just families that were affected with COVID, losing loved ones and just being scared of the world or going back out in the world after all this passes."

> "Preparing ourselves a little because of everything we were seeing. Including our own mental health because if our mental health is not well, how are you going to help other people? [...] We took the first 6 session training on different topics, but all based on mental health. I think that's very important, mental health training, so we don't try to bear all the burden ourselves [...] well it is part of our job to help search for resources, but if someone is not well, I don't think we could do a good job. So, I think a mental health training program would be good."

In addition to mental health topics, CHW/R participants described the importance of maintaining physical health and wellbeing during the pandemic. CHW/Rs reported challenges in their clients managing chronic diseases, especially during periods of isolation. To support their clients, CHW/Rs recommended incorporating nutrition, physical activity, and chronic disease management topics into COVID-19 prevention training to further develop their own knowledge and skills in these areas. Thinking of long-term solutions, CHW/Rs suggested that training in this area should prepare CHWs and clients to adapt to new lifestyles during and after quarantine to manage and reduce the risk of chronic diseases.

> "Most of our patients have health issues like diabetes and high blood pressure and stuff like that. And then just from the clinic side from being in quarantine and their numbers have gone up a lot on their sugars and blood pressure is not really well controlled anymore."

> "The coronavirus is touching too many people, and this is the topic of the day. But I feel that the basis in that global training where we cannot separate the vaccine from the diet, from the physical training, that is, it is a comprehensive training to manage a new lifestyle."

3.2. Development and implementation of CHW/R workforce capacity building strategies

NAU-AzCHOW held regular virtual meetings throughout the research process, equitably contributing to the development of data collection tools, participant recruitment, and data analysis and interpretation – each team leveraging their respective and collective expertise, capacity, and strengths. While NAU researchers led data collection and analysis, information shared during focus groups was discussed in weekly team meetings with AzCHOW. Team meetings consisted of a trusted space where NAU and AzCHOW staff engaged in open knowledge sharing of salient themes from focus groups as well as anecdotes from personal relationships with CHW/Rs and community members. In line with AZ-CEAL aims 2 and 3, AzCHOW then led the development of health education materials and training for CHW/Rs to use with their communities based on priority topics identified from team conversations.

NAU-AzCHOW partnered to engage in CHW/R workforce capacity building during the pandemic, using focus group conversations to identify priority educational topics for CHW/Rs to better support their clients. As a result, AzCHOW developed and offered topic specific training in English and Spanish to the CHW/R workforce in Arizona, focusing on COVID-19 vaccines and spanning topics such as vaccine content, safety, and effectiveness, vaccine hesitancy, and addressing misinformation. Training style and delivery format were also driven by CHW/R input. For example, to address safety concerns and reach as many CHW/Rs as possible, synchronous training on vaccine topics and COVID-19 misinformation were offered virtually *via* Zoom during a time in the pandemic when vaccines were not widely accessible to all communities and vaccine uptake was low. Furthermore, AzCHOW adapted and expanded the synchronous virtual training on vaccines to an asynchronous online format, consisting of a 7-part series of training videos (35) on the following topics: (1) introduction to the COVID-19 vaccine video series; (2) COVID-19 vaccines available; (3) the development of COVID-19 vaccines; (4) deciding to get vaccinated; (5) speaking with clients about the vaccines; (6) COVID-19 vaccine myths or facts; and (7) educational resources. The 7-part series was created with intentionally short and concise videos, broken up by topics so that CHW/Rs could engage in learning at their own pace and be able to use the videos with their clients to provide education. The series was made available online on the NAU CEAL website in both English and Spanish and shared *via* the AzCHOW email listserv, including with CHW/Rs who participated in the focus groups.

Responding to CHW/R needs as expressed during focus group conversations, AzCHOW also developed and offered an online synchronous training focused on mental health support for CHW/Rs themselves, including topics of grief, isolation, and loss in the context of COVID-19. When vaccines became widely available to the public, AzCHOW developed and offered another online synchronous training for CHW/Rs on using motivational interviewing skills to build vaccine confidence in vaccine-hesitant clients. To date, AzCHOW has trained over 220 CHW/Rs representing 30 employers across the state of Arizona, including tribal CHR programs, federally qualified community health centers, and organizations offering social services, on priority topics identified during the focus group conversations. NAU and AzCHOW are also co-developing and implementing tools to evaluate and improve CHW/R training.

The NAU-AzCHOW team experienced some difficulties in developing the CHW/R training based on priorities identified during the focus groups. Evidence-based CHW/R curriculum and training to model in the design of training and other materials were limited.

TABLE 2 Community health worker/representative ($N = 46$) vaccine likelihood, COVID-19 prevention behaviors, and trusted sources of information – combined phases 1 and 2.

Variable	Percent (Frequency)			
Likelihood of getting a COVID-19 vaccine				
Not at all	6.5% (3)			
3	2.2% (1)			
4	6.5% (3)			
5	2.2% (1)			
6	2.2% (1)			
Very likely	80.4% (37)			
COVID-19 prevention behaviors when in public in the past 7 days	**Never**	**Some of the time**	**Very often**	**All of the time**
Hand washing	–	–	10.9% (5)	89.1% (41)
Mask use	2.2% (1)	2.2% (1)	8.7% (4)	87.0% (40)
Social distancing	–	4.4% (2)	39.1% (18)	56.5% (26)
How much do you trust each of these sources to provide correct information about COVID-19?	**Not at all**	**A little**	**A great deal**	**Don't know**
Your doctor or health care provider	2.2% (1)	23.9% (11)	73.9% (34)	–
The U.S. Coronavirus Task Force	2.2% (1)	50.0% (23)	43.5% (20)	2.2% (1)
Your faith leader	15.2% (7)	30.4% (14)	34.8% (16)	19.6% (9)
People you go to work or class with or other people you know	2.2% (1)	60.9% (28)	23.9% (11)	13.0% (6)
Arizona State Government	8.7% (4)	60.9% (28)	23.9% (11)	6.5% (3)
The U.S. government	15.2% (7)	60.9% (28)	19.6% (9)	4.4% (2)
Your close friends and members of your family	8.7% (4)	60.9% (28)	19.6% (9)	10.9% (5)
Local Tribal Government	8.7% (4)	50.0% (23)	19.6% (9)	21.7% (10)
Neighboring Tribal Government	10.9% (5)	47.8% (22)	15.2% (7)	26.1% (12)
News on the radio, TV, online, or in newspapers	21.7% (10)	58.7% (27)	8.7% (4)	10.9% (5)
Your contacts on social media	54.4% (25)	37.0% (17)	–	8.7% (4)

This required more creativity, and therefore additional time, from the team to develop training and materials. Another challenge was the ever-evolving nature of COVID-19 information, demanding that content be frequently updated. Similarly, information needed to be simplified into plain language for CHW/Rs to understand and be able to use with their clients. Training and materials then had to be translating into Spanish, ensuring cultural relevance in the translation. Translation resulted in time constraints since it could only be done by bilingual, bicultural team members. Furthermore, training and materials were pilot tested before full launch to ensure that content and delivery were effective and relevant. However, pilot testing was inconsistent, primarily due to staff time limitations, availability of CHW/Rs, and urgency (i.e., CHW/Rs needed up-to-date COVID-19 information quickly).

Despite challenges, NAU and AzCHOW effectively partnered to use research findings to inform rapid decision-making and action in the COVID-19 response. As COVID-19 continues to evolve, AZ-CEAL has also adapted to be culturally responsive and relevant to community needs. The latest effort of the NAU-AzCHOW partnership is a movement toward long COVID, with development of a training for CHW/Rs spanning topics of what long COVID is, prevention, management, and resources.

4. Discussion

During the pandemic, CHW/Rs have experienced a heightened role in supporting clients, including sharing critical and accurate information about COVID-19, linking them to essential services across the social determinants of health, and providing social connection during a time of isolation. Despite their documented effectiveness across health outcomes and settings on a global scale, CHW/Rs continue to be insufficiently engaged as experts in the US health care and public health systems, including in the pandemic response (11, 16, 17). The importance of CHW/Rs, including their role as key players in the frontline COVID-19 pandemic response, must be acknowledged with action that invests in a sustainable national CHW workforce. Building strong organizational culture supportive of CHW/R professional development and teams to respond to COVID-19 is essential.

4.1. CHW/R public health recommendations

CHW/R focus group participants raised a number of primary takeaways for an effective community-grounded pandemic response to address pressing needs in their Latinx and American Indian clients and support the prevention of COVID-19:

1. Implement culturally and linguistically relevant policies, programs, and resources to support clients at high risk for COVID-19, including non-English speaking, immigrant, elderly, homebound, and homeless communities.
2. Develop culturally and linguistically relevant mental health resources to support the isolation, grief, and loss disproportionately experienced due to COVID-19.
3. Create culturally and linguistically relevant materials to support COVID-19 prevention behaviors, including child and family member isolation due to schools' closure and quarantine.
4. Integrate COVID-19 prevention with chronic disease management, especially during periods of isolation and quarantine.
5. Improve public trust in public health recommendations and messaging to dispel myths and correct misinformation.
6. Invest in the professional development and preparation of the CHW/R workforce to serve their communities with culturally and linguistically relevant evidenced based materials and tools.

Using highly participatory methods, this academic-community partnership supported CHW/R workforce capacity building efforts in the context of COVID-19 to contribute to a community-grounded pandemic response. Our work aligns with best practices in CHW/R workforce engagement in research (28), contributing to better production of knowledge guided by CHW/R expertise. This is exemplified through a collaborative approach with the statewide association AzCHOW to develop data collection tools together, engage CHW/Rs throughout the research process such as in pilot testing the tools, and hold focus groups and special topic training in both English and Spanish.

Uniquely, NAU and AzCHOW teams reflect the diversity of communities of focus for AZ-CEAL, including bicultural, bilingual, racially-ethnically, and geographically diverse team members with a mix of professional and personal lived experiences. Throughout the research process, NAU-AzCHOW partners engaged in ongoing and open dialogue about what CHW/Rs on the ground were reporting as priority community concerns, needs, and challenges. CHW/Rs informed the development of culturally and linguistically relevant health education messages, materials, and training for CHW/Rs.

The CHW/R workforce in Arizona includes a unique population of Spanish-speaking CHWs or promotores de salud serving Latinx clients and indigenous tribally-employed CHRs serving AI clients. Unique to this study is the integration of perspectives of promotores and CHRs, which have historically distinct interests due to differences in origins and populations served among other factors (36). Building capacity across the two is essential in unifying and strengthening the CHW/R workforce, which in turn better positions the workforce for continued recognition and funding (36). The work of NAU-AzCHOW through AZ-CEAL provides a distinctive example of how research teams and statewide CHW associations can partner to facilitate knowledge sharing and create community-grounded resources to support CHW/R workforce capacity building in the context of a pandemic.

5. Conceptual or methodological constraints

Given the small sample size and focus on CHW/Rs employed in Arizona and serving primarily Hispanic/Latinx and American Indian clients, the research findings may not be generalizable to other communities or regions in the US. Another limitation of this study is the lack of African American CHW/R client representation. CEAL aims to work closely with the communities who have been most impacted by the pandemic, including Hispanic/Latinx, American Indian, and African American populations. Multiple attempts through a variety of networks to engage African American CHW/Rs in focus group conversations, including by research staff identifying as African American, were unsuccessful due to lack of strong relationships between the research team and organizational partners. This may also be explained partly by the low percentage of African American residents in the state compared to nationally (5.2 vs. 13.4%, respectively) (24). For the survey data, bivariate analyses were conducted and no significant differences were found between Latinx and AI participants. Additionally, since a majority of participants identified as women (89%), bivariate analysis in gender identity was not appropriate. Therefore, all results were reported aggregated.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by the University of Arizona Institutional Review Board (Protocol # 2011244240). Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

DJ and SS lead the writing of the community case study. OG, RM, AP, LE, NL, MI, KG, RR, FR, HW, SO, and SP participated in the development of the research protocol, including its conceptualization and data collection tools. DJ, OG, RM, AP, LE, KG, RR, FR, and SS were involved in data collection, analysis, and interpretation. Each provided a detailed review of focus group data draft reports and reviewed the final versions of the community case study. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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EDITED BY
E. Lee Rosenthal,
Texas Tech University Health Sciences Center El Paso, United States

REVIEWED BY
Enyi Ifeoma Etiaba,
University of Nigeria, Nigeria
Naomi Lee,
Northern Arizona University, United States

*CORRESPONDENCE
Kim Bush
✉ kim.bush@uthct.edu

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Unsung heroes in health education and promotion: How Community Health Workers contribute to hypertension management

Kim Bush[1]*, Carlea Patrick[1], Kimberly Elliott[2], Michael Morris[2], Yordanos Tiruneh[1,3] and Paul McGaha[1]

[1]Department of Preventive Medicine and Population Health, University of Texas at Tyler Health Science Center, Tyler, TX, United States, [2]Department of Health Policy, Economics, and Management, University of Texas at Tyler Health Science Center, Tyler, TX, United States, [3]University of Texas Southwestern Medical Center, Dallas, TX, United States

Rural communities are noted as having poor health outcomes. Rural areas experience barriers to care primarily due to a lack of resources, including education, health insurance, transportation, and social support. Additionally, poor health outcomes are a consequence of poor health literacy skills. Community Health Workers (CHWs) are utilized as a resource to combat these issues. This study focused on a CHW led Self-Management Blood Pressure (SMBP) program offered through the University of Texas at Tyler Health Science Center. The goal of the program was to improve management of hypertension through awareness, education, navigation, advocacy, and resource assistance. The SMBP program included structured workshops and regular follow-up with participants including connections to community resources and social support. CHWs worked closely with physicians providing bi-directional feedback on referrals and engagement of communities through outreach events. Furthermore, CHWs aided to bridge cultural or linguistic gaps between service providers and community members. Data is provided indicating this CHW-led intervention played a significant role in improving hypertension through education of how to make lifestyle changes that impact overall health and quality of life. Participants gained knowledge encouraging them to create lifelong healthy habits, coping skills, stress management, self-care, and accountability. Through this innovative approach, participants thrived in the supportive and encouraging environment led by CHWs as well as improved their blood pressure management.

KEYWORDS

Community Health Workers, health outcomes, health education, health promotion, self-management

Introduction

Cardiovascular disease and stroke are respectively the number one and five leading causes of death in the United States (1) and in Northeast Texas (2). Northeast Texas is documented as one of the least healthy regions of the state, with a prevalence of chronic disease significantly above both state and national averages (2). While these statistics have remained stable over time (1, 2), it is widely recognized that hypertension is a modifiable risk factor for both deadly conditions (3). Improving the control of hypertension is a complex task, which is compounded in rural regions such as Northeast Texas. It is well documented that in rural communities there is less access to care, the quality of care is often lower, and community resources are less readily available to support health within the community (4, 5). A class of strategies that has been utilized to attempt to overcome the complexity of hypertension management among rural (6, 7) and other underserved populations (8) are Community Health Workers (CHW) led interventions.

CHWs are known to build community capacity in efforts to improve health outcomes. Additionally, CHWs play a significant role in shifting the trajectory of chronic disease by encouraging lifestyle changes that impact overall health and quality of life (9). CHWs also serve to bridge cultural and/or linguistic gaps between service providers and community members. By providing education and resources to improve health literacy about symptoms, negative consequences, and treatment outcomes associated with chronic illness, CHWs empower individuals to play an active role in reducing the severity of their chronic illness.

CHWs play an important role in their communities, providing services at the individual and group level (10, 11). According to the American Public Health Association (12), CHWs are trusted in communities they serve which results in improved relationships between community members and health and social service organizations. Additionally, given proper training, CHWs provide health knowledge through individual and community capacity building through various screening and educational activities (13). Furthermore, Hartzler et al. (14) observed that CHWs provide self-management support to patients through counseling involving collaborative goal setting, problem-solving, and action-planning. Their strength derives in part from their building relationships on trust, emotional attendance, and authenticity (15). Although CHWs are widely known across the nation, the profession may not be utilized to its potential or fully recognized as essential in the broader landscape of chronic disease management.

CHW led interventions have been shown to be effective in the management of non-communicable health conditions (16). For example, the Education to Promote Improved Cancer Outcomes (ÉPICO) project, utilized Spanish-speaking CHWs or promotors, to enhance cancer knowledge among residents of the Rio Grande Valley of Texas (17). Similarly, CHW led interventions have been effective in changing health behaviors among minority populations with diabetes (18). The evidence on CHW's influence on the prevention and management of hypertension extends at least back to the 1970s, with benefits demonstrated in improved health related knowledge and behaviors, and blood pressure reduction (19). More recent systematic reviews by Kim et al. (20) Scott et al. (21), and Cabellero et al. (22) further illustrate that CHW led interventions can be effective in improving the management of chronic disease, including hypertension, among rural and other vulnerable populations.

This study examines the outcomes of a hypertension focused CHW-led Self-Management Blood Pressure (SMBP) program operated by the University of Texas at Tyler Health Science Center. The population of interest is people living with hypertension in Northeast Texas. This study: (1) describes a CHW-led SMBP workshop series designed to improve health outcomes among patients with hypertension receiving care at a rural academic health center; (2) evaluates the program's impact on participant knowledge and behavior regarding blood pressure management before and after completion of the program; (3) assesses the effect of the intervention on hypertension control from blood pressure measures taken at baseline and at the end of the program; and (4) reports participants perceptions and experiences of the program.

Materials and methods

The University of Texas at Tyler Health Science Center's Self-Management Blood Pressure (SMBP) program is a multi-component lifestyle change intervention that combines and adapts evidence-based components from lifestyle change and hypertension management curricula disseminated by the National Heart, Lung, and Blood Institute (23) and the American Heart Association (24) and TARGET:BP collaboration between AHA and American Medical Association (25). Using these materials, a hybrid curriculum was developed into a 12-week hypertension-management workshop series. Additional materials were provided by the Texas Department of State Health Services (DSHS).

The process began with an orientation session during which participants learned more about the program and completed all required paperwork including an informed consent form before participating in the program. Participants who agreed to join the program were provided blood pressure monitors to use throughout the program and upon graduation they were allowed to keep the apparatus. Participants were taught how to use the blood pressure monitor according to TARGET:BP (26) guidelines and tasked with checking their blood pressure twice daily (once in the morning and once in the evening). Participants were also required to record their daily BP (blood pressure) readings in a blood pressure booklet (My Blood Pressure Passport) Texas Department of State Health Services and Texas Health and Human Services (27) developed by the Texas Heart Disease and Stroke Program and Health Promotion and Chronic Disease Prevention section through the Texas Department of State Health Services (DSHS) and Texas Health and Human Services (HHSC). Additionally, participants were encouraged to share this document with their primary care providers. The workshop participants met bi-weekly over 12 weeks for ∼1 h. During these sessions, CHWs provided heart health education to the participants and collected blood pressure readings from the preceding 2-week period. These data were de-identified and stored electronically in a secured file. De-identified data was also shared with DSHS upon cohort graduation. Participants received a $5 gas/gift card upon attendance and participation in the bi-weekly sessions. Participants who completed the entire workshop series were awarded the blood pressure monitor that they used during the program as well as a certificate of successful completion upon graduation. Furthermore, participants were invited to attend a 3-, 6-, 9-, and 12-month follow-up reunion where they acquired additional educational information as well as continued support for maintaining their blood pressure at healthy levels. As an additional incentive, participants were also presented with a $5 gas/gift card for attending post-program follow-up sessions.

The SMBP program is a community-based health program therefore participants self-selected into the program. No statistically based sampling method was employed in the selection of participants, it was a convenient sample. Participants in the SMBP program were recruited from the East Texas community at large through several methods: (i) The primary modes of recruitment were through referrals from University of Texas Health East Texas (UTHET) physician clinics and by word-of-mouth referrals from persons who had previously participated in the program. (ii) UTHET Emergency Medical Services Mobile Integrated Health unit also provided referrals for some of their patients to the SMBP program. (iii)

Community outreach fairs and presentations at assisted living centers and the Tyler Library contributed the remaining SMBP participants.

The SMBP sessions included in this study were conducted from August 2019 to June 2022. Three separate data sets, capturing different dimensions of program performance, were collected from persons who enrolled in and participated in the SMBP program. These were (1) the assessment of changes in participant knowledge and behaviors, (2) change in systolic and diastolic blood pressure and, (3) the participants' self-reported experiences of completing the SMBP program.

Assessment of changes in participant knowledge and behaviors

Participants completed knowledge and skills assessments related to blood pressure management at the start of the program and then upon program completion. The pre-test was comprised of a 5-question knowledge exam followed by a three-question self-assessment of the participant's skills for controlling hypertension. This pre-test was self-administered at the time the individual enrolled in the program. The post-test repeats the questions from the pre-test and is administered at the graduation ceremony from the program. Because results from the pre- and post-test were collected anonymously and tabulated in the aggregate for record retention, we were unable to present measures of significance for the variation in the data.

Assessment of changes in systolic and diastolic blood pressure

CHWs taught participants how to accurately take their own blood pressure using the automated arm-cuff monitor so that they were able to record daily blood pressure readings in their booklet, My Blood Pressure Passport.

A one group pre-test/post-test design was utilized to assess changes in the participants' mean blood pressure, with separate analyses conducted for changes in systolic and diastolic blood pressure. The pre-test time point was defined as the time of the blood pressure reading taken during the program's first-week session. The post-test time was defined as the time of the measurement conducted during the program's last session week 12. Participants measured their blood pressures in millimeters of mercury using the Omron 7 Series Blood Pressure Monitor and following American Heart Association/American Medical Association TARGET:BP: SMBP guidelines (26). Separate paired sample *t*-tests were utilized to assess the hypotheses that there were no differences between pre- and posttest mean systolic and diastolic blood pressures for the study population. Within group changes in mean blood pressure were assessed for each participant's characteristics available in the data, including age, gender, race, ethnicity, education level, body mass index (BMI), whether the individual was currently on antihypertensive medications, whether they had ever smoked, and whether they were subject to additional comorbidities, diabetes and/or cardiovascular disease. Based on the demographic composition race was defined in this study as being White or Black. Ethnicity was defined as either Hispanic or non-Hispanic. Racial and Ethnic categories are not considered to be mutually exclusive, for example, an individual can be Black and Hispanic or Black and non-Hispanic. Race and Ethnicity data were self-reported by participants. Underlying assumptions for the use of paired *t*-tests were assessed, with no influential outliers noted, and the results of a Shapiro-Wilk test of normality met the requirement for approximate normality. All analyses were conducted using STATA version 16. Statistical significance was set at the 0.05 level.

Assessment of participant experience

The final data source utilized in this study was a participant experience survey completed at the end of the week 12 intervention. This was a self-administered survey. Responses were anonymous and tabulated at the aggregate level for record retention. The instrument was comprised of five-questions that used a Likert format gauging agreement with the base question on a scale of strongly agree to strongly disagree. All individuals who finished the SMBP program completed at least part of the survey. Because response data were retained at the aggregate level, we were not able to calculate measures of significance for variation in responses. In addition to the formatted questions, participants were invited to provide any additional comments in free form text. For the purposes of reporting here, the responses were divided into four categories, (i) including constructive comments about the CHWs who ran the workshop, (ii) the workshop content, (iii) delivery mode, and (iv) the overall experience with the program.

Results

Total enrollment for these SMBP cohorts was 242. Enrollment in the program consists of a participant's agreement confirmed by a signed consent to participate in the program. The consent was delivered to potential participants by email and then electronically signed and returned prior to attending the orientation session. The actual number of participants who started the program was 212, which includes a signed consent form, attendance at the orientation or session one, and providing a minimum of one blood pressure reading. Of these enrollees, 197 completed the program by regularly providing blood pressure readings. However, five of the 197 participants failed to complete all 12 weeks of the program and thus did not provide blood pressure readings at the final week of the program leaving us with 192 subjects included in the blood pressure analytical file. The decline from participant enrollment (242) to participants who completed the program (197) could be attributed to multiple factors including, lost to follow-up, family emergencies, COVID-19 pandemic related stress and/or anxiety, over commitment, and other causes. Comparison of the individuals who were dropped from the study sample with those included in the analysis showed no statistically significant differences in gender ($p = 0.32$), race ($p = 0.43$), age ($p = 0.65$), or education level ($p = 0.28$).

Table 1 shows the demographic and health-related characteristics of participants in the program. Our sample skewed older (69.4%) and over three fourth (76.6%) were female. Whites (72.9%) were the predominant racial group (Blacks 27.1%) represented in the study population and non-Hispanics (82.3%) were the more prevalent ethnic group (Hispanics 34.0%). The educational level of participants was evenly distributed, with a slight majority having earned at least

TABLE 1 Characteristics of study participants.

Characteristic	Study population
	N (%)
Overall	192
Age in years	
20–39	17 (8.85)
40–59	61 (31.77)
60–79	106 (55.21)
>79	8 (4.17)
Sex	
Female	147 (76.56)
Male	45 (23.44)
Race[#]	
Black	52 (27.08)
White	140 (72.92)
Ethnicity[#]	
Hispanic	34 (17.71)
Non-Hispanic	158 (82.29)
Education	
<High school	34 (17.71)
High school	43 (22.40)
Some college	57 (29.69)
College or more	58 (30.21)
Body mass index	
Normal	21 (10.94)
Overweight	46 (23.96)
Obese	125 (65.10)
Hypertension medicine	
Yes	142 (73.96)
No	50 (26.04)
Smoker	
Yes	43 (22.40)
No	149 (77.60)
Cardiovascular disease	
Yes	44 (24.72)
No	134 (75.28)
Diabetes	
Yes	58 (31.35)
No	127 (68.65)

[#] Race and Ethnicity in this study are conceptualized as separate non-mutually exclusive characteristics. Race is operationalized as White or Black and Ethnicity is operationalized as Hispanic or non-Hispanic. For example, an individual can be both Black and Hispanic or Black and non-Hispanic. Race and Ethnicity data is self-reported by participants.

TABLE 2 Participant pre-test/post-test hypertension knowledge.

Questions	Pre-test correct	Post-test correct
	n (%)	*n* (%)
Question 1. Which of the following are risk factors for heart disease and stroke? a. Smoking b. High levels of blood cholesterol c. Diabetes d. High blood pressure e. All of the above	204 (88)	179 (91)
Question 2. What are some things you should NOT do when checking your blood pressure? a. Cross your legs b. Take a deep breath c. Have a conversation d. All of the above	203 (84)	175 (89)
Question 3. Which of the following is a normal blood pressure reading? a. 170/80 b. 160/90 c. 120/80	210 (91)	191 (98)
Question 4. What is the top number of a blood pressure reading called? a. Systolic b. Metabolic c. Diabolic	191 (88)	175 (93)
Question 5. What is the bottom number of a blood pressure reading called? a. Diastolic b. Metabolic c. Anabolic	179 (82)	174 (92)

some college credit. BMI skewed significantly toward obesity, with 65.1% of participants falling into this category. Similarly, participants were highly likely to be currently on blood pressure medication (73.9%). Regarding comorbidities, 31.4% reported being diabetic, while 24.7% suffered from diagnosed cardiovascular disease. Fewer than a quarter (22.4%) of the participants reported a history of smoking.

Results assessment of changes in participant knowledge and behaviors

As depicted in Tables 2, 3, survey results indicate that among participants in the SMBP program there was a high baseline level of knowledge and skills regarding blood pressure management. Despite the high proportion of participants at baseline who answered knowledge questions correctly and indicated that they agreed or strongly agreed with the statements about their hypertension management abilities, post-test results indicated improvement across board on the measures captured in the surveys. Of note, are the increases in self-reported knowledge on how to take blood pressure (pre-test 83% to post-test 99%), understanding how to read blood pressure measurements (pre-test 85% to post-test 100%), and taking their blood pressure medication (pre-test 76% to post-test 86%).

Results assessment of changes in systolic and diastolic blood pressure

Results of our paired t-test analyses of change in blood pressure, presented in Table 4, indicate that, for the overall study population

TABLE 3 Pre-test/post-test confidence in hypertension management skills.

Statement	Pre-test Agree or strongly agree *n* (%)	Post-test Agree or strongly agree *n* (%)
Statement 1.	191 (83)	193 (99)
I know how to take my blood pressure. a. Strongly agree b. Agree c. Disagree d. Strongly disagree		
Statement 2.	199 (85)	194 (100)
I understand how to read my blood pressure. e. Strongly agree f. Agree g. Disagree h. Strongly disagree		
Statement 3.	186 (76)	166 (86)
I take my blood pressure medication. i. Strongly agree j. Agree k. Disagree l. Strongly disagree		

mean systolic blood pressure dropped by 4.48 mm/Hg from the beginning through the end of the study ($p < 0.05$). The association between the intervention and a statistically significant drop in mean systolic blood pressure was found for both women and men as well as for all racial and ethnic groups in the study population. Similarly, significant reductions in mean systolic blood pressure were observed for both those currently on blood pressure medications and those not taking medications. Individuals who had not earned college degrees experienced a significant reduction in mean systolic pressure, while those with college degrees experienced a non-significant decline. Individuals who were overweight or obese experienced significantly lower mean systolic blood pressure, but reductions for participants of normal weight did not reach statistical significance. Program participants who smoked or had diabetes experienced significant decreases in systolic pressure, but those with cardiovascular disease did not.

The results for diastolic blood pressure, presented in Table 4, showed significant reductions, on average 2.73 mm/Hg for the study population over the study period. Significantly lower readings were observed at time point 12 for both males and females and for Non-Hispanics and Whites. Blacks and Hispanics experienced lower mean diastolic blood pressure but did not meet the threshold for statistical significance. Participants between the ages of 40 and 79 experienced statistically significant lower diastolic blood pressure, while the lower readings in blood pressure obtained among the older and younger participants did not reach significance. While lower mean diastolic blood pressures were achieved across education groups, these readings reached significance only for the individuals with some college education. As was seen with systolic blood pressure, diastolic blood pressure was significantly lower in week 12 among overweight and obese individuals but failed to reach significance for participants of normal weight. Both smokers and non-smokers experienced statistically significant drops in diastolic blood pressure as did those taking antihypertensive medications. Statistically significant improvements in diastolic blood pressure were observed for both diabetics and non-diabetics. No significant reductions in diastolic blood pressure were observed for individuals with cardiovascular disease.

Results assessment of participant experience

Findings from the participant experience surveys, presented in Table 5, illustrate that the SMBP program was both easy to understand and useful in helping participants to increase their knowledge of hypertension and hypertension management. Almost all (99%) either agreed or strongly agreed that the SMBP program was easy to understand. An overwhelming majority indicated that the program helped them to understand facts about hypertension (99% agreed or strongly agreed) and understand the complications of hypertension (99% agreed or strongly agreed). Similarly, most respondents felt that their questions about hypertension were answered and that they know how to use their blood pressure cuff.

In addition to completing the participant experience survey, forty-eight percent (48%) of participants completing the SMBP program provided written feedback at the end of the 12-week program. These free form comments provide a qualitative perspective on the program. Three percent (3%) of participants who provided feedback felt the program should include additional visual aids, experienced issues with virtual connectivity, or commented on the time of day a specific workshop occurred. Twenty-two percent (22%) of participants felt the content presented by CHWs was helpful in creating healthier lifestyle habits.

Discussion

This study evaluates a CHW-led hypertension self-management program implemented among 197 participants in rural northeast Texas. We used three different data sources to evaluate the program. These were: a pre-test knowledge and skills assessment survey, an assessment of change in systolic and diastolic blood pressure before and after the 12-week program, and an assessment of participants' experience with the program after the completion of the intervention. The study found that knowledge about hypertension and hypertension management has improved. Participants showed behavioral change in hypertension management as measured by monitoring their blood pressure at home regularly and taking their medication as prescribed. Changes in both systolic and diastolic blood pressure were observed between mean baseline and last (at the end of the 12-week program) BP measures across subpopulation groups. Finally, participants expressed positive experiences of the program in terms of the information that they were able to obtain as well as the ease of understanding the content.

Knowledge about hypertension and hypertension management improved from baseline measurements. From a conceptual perspective, the increase in participant awareness of the risks of hypertension and understanding of the management of their

TABLE 4 Change in mean systolic and diastolic blood pressure mm/Hgb time 1 to time 12.

Characteristic	Mean time 1	Mean time 12	Mean time 1	Mean time 12
	Systolic blood pressure	Systolic blood pressure	Diastolic blood pressure	Diastolic blood pressure
	mm/Hg	mm/Hg	mm/Hg	mm/Hg
	(Std. err.)	(Std. err.)	(Std. err.)	(Std. err.)
Overall (*n* = 192)	135.36 (1.23)	130.88 (1.19)*	82.05 (0.82)	79.32 (0.76)*
Age in years				
20–39	125.90 (3.14)	119.92 (2.89)	85.23 (3.12)	80.53 (2.00)
40–59	134.22 (2.34)	131.54 (2.37)	84.93 (1.39)	82.41 (1.45)*
60–79	136.91 (1.55)	131.79 (1.49)*	80.16 (1.04)	77.60 (0.97)*
>79	143.68 (7.76)	137.23 (5.61)	78.34 (5.32)	76.05 (3.68)
Sex				
Female	134.08 (2.25)	129.53 (1.32)*	80.73 (0.92)	78.49 (0.83)*
Male	139.56 (1.44)	135.30 (2.58)*	86.37 (1.64)	82.05 (1.71)*
Race#				
Black	136.05 (2.28)	136.05 (2.28)*	82.17 (1.85)	79.62 (1.59)
White	135.11 (1.46)	135.11 (1.46)*	82.01 (0.89)	79.21 (0.85)*
Ethnicity#				
Hispanic	131.94 (3.92)	126.23 (3.19)*	79.90 (2.20)	77.44 (2.11)
Non-Hispanic	136.10 (1.23)	131.89 (1.26)*	82.52 (0.87)	79.73 (0.80)*
Education				
<High school	130.91 (3.03)	127.16 (3.09)*	78.30 (2.09)	76.05 (2.15)
High school	142.28 (3.09)	136.40 (3.09)*	84.91 (1.88)	82.44 (1.80)
Some college	136.53 (2.07)	130.29 (1.82)*	83.92 (1.18)	79.85 (1.07)*
College or more	131.70 (1.80)	129.57 (1.85)	80.30 (1.51)	78.41 (1.28)
Body mass index				
Normal	132.35 (3.99)	129.41 (3.23)	81.24 (2.34)	80.44 (1.90)
Overweight	133.31 (2.67)	129.39 (2.58)*	81.43 (1.84)	78.97 (1.65)*
Obese	136.63 (1.47)	131.68 (1.47)*	82.42 (0.99)	79.26 (0.94)*
Hypertension medicine				
Yes	136.94 (1.44)	132.37 (1.40)*	81.81 (0.95)	79.17 (0.91)*
No	130.88 (2.28)	126.66 (2.14)*	82.74 (1.61)	79.76 (1.35)
Smoker				
Yes	142.21 (2.48)	135.76 (2.81)*	84.96 (1.92)	80.15 (1.66)*
No	133.39 (1.38)	129.48 (1.28)	81.22 (0.89)	79.09 (0.85)*
Cardiovascular disease				
Yes	140.40 (2.59)	137.10 (2.93)	80.55 (1.63)	78.32 (1.75)
No	132.14 (1.29)	127.48 (1.16)	81.69 (0.93)	78.87 (0.83)
Diabetes				
Yes	138.51 (2.26)	133.71 (2.15)*	80.88 (1.39)	78.86 (1.47)*
No	133.68 (1.52)	129.60 (1.46)	82.82 (1.03)	79.87 (0.90)*

*Denotes a statistically significant change in mean systolic or diastolic blood pressure at the p < 0.05 level based on paired t test.

#Race and Ethnicity in this study are conceptualized as separate non-mutually exclusive characteristics. Race is operationalized as White or Black and Ethnicity is operationalized as Hispanic or non-Hispanic. For example, an individual can be both Black and Hispanic or Black and non-Hispanic. Race and Ethnicity data is self-reported by participants.

TABLE 5 Participant experience survey data ($n = 189$).

Questions	Strongly agree (=4)	Agree (=3)	Disagree (=2)	Strongly disagree (=1)	Median (interquartile range)
	n (%)	*n* (%)	*n* (%)	*n* (%)	
Question 1. The workshop helped me to understand facts about hypertension	153 (80.95)	35 (18.52)	0 (0)	1 (0.53)	4 (4, 4)
Question 2. The workshop helped me understand complications of hypertension	153 (80.95)	35 (18.52)	0 (0)	1 (0.53)	4 (4, 4)
Question 3. The workshop did not answer all my questions about hypertension	16 (8.47)	13 (6.88)	61 (32.28)	95 (50.26)	1 (2, 1)
Question 4. The information provided in the workshop was easy to understand	156 (82.54)	32 (16.93)	0 (0)	1 (0.53)	4 (4, 4)
Question 5. I am not able to adequately use my blood pressure cuff at home	9 (4.76)	6 (3.17)	43 (22.75)	131 (69.31)	1 (2, 1)

condition are the first steps toward improving health outcomes. In our study, participants demonstrated increased awareness (from 88% to 91%) that high blood pressure was a risk factor for heart disease and stroke. Similarly, knowledge of proper technique for taking blood pressure (83% to 99%) and interpreting its measurement (85% to 100%) improved from baseline to the week 12 assessment. These findings are conceptually consistent with those found by Boulware et al. (8) where CHW led training was linked to improved hypertension problem solving capabilities including self-management knowledge.

Our findings showed that participants reported an improved behavior to monitor their hypertension and take their medications. The majority (92%) of the participants reported that they were able to adequately use their BP cuffs at home to monitor their blood pressure regularly. Adherence to hypertension medication also improved as 86% of the participants self-reported taking their medications properly after the program compared to (76%) of those who did so before the intervention. These findings are similar to other CHW-led interventions designed to improve disease control and medication adherence. These includes interventions for diabetes and/or hypertension program in Mexico (28), Diabetes Self-Management Education Program in the US (29), and CHW-led intervention in Tanzania in HIV (Human Immunodeficiency Virus) infected pregnant mothers to improve adherence and retention to care (30). The reported behavioral change in most of these programs could be due to CHW's ability to spend more time to educate patients than providers would be able to. Thus, patients are more likely to ask all their questions and be willing to apply the suggested behavioral changes. It is, however, important to examine if these changes are long-lasting past the intervention's completion as most of these studies, including ours, assessed change shortly after the completion of the program. It will be important to continue to monitor graduates from the SMBP program to assess long-term patient adherence as longer monitoring, even at a distance has been reported to increase the likelihood of patient adherence in maintaining a healthy BP range (31). Thus, there is a need for high-quality, rigorous studies to determine long term effectiveness of CHW-led interventions on medication adherence and control of chronic conditions.

Our study participants experienced changes in blood pressure measures (both systolic and diastolic) after the 12-week intervention. Analyses of changes in blood pressure indicated an association between the Self-Management Blood Pressure (SMBP) hypertension program and reductions in both mean systolic and diastolic blood pressure among a sample of 192 individuals from a region of Texas that faces complex, well-documented health challenges (2). The mean difference in baseline and final (at the end of the 12-week program) systolic measure was 4.8 mm/Hg, and the number of diastolic BP was 2.73 mm/Hg. This change was experienced by all patients across all participants. Significant reductions were associated with the program among both men and women and across racial and ethnic groups. While these findings must be viewed cautiously because of design elements, including a relatively small sample size, the lack of a control group, and the reliance on only one pre- and one post-test time points, they do support growing consensus in the literature that CHW-led interventions lighten the community burden caused by chronic diseases (9). Among the most encouraging findings regarding this CHW-led SMBP intervention is the broad-based impact that it is associated with on systolic blood pressure. This is important, as many see systolic blood pressure as the more pivotal marker of hypertension control among older adults such as comprise the overwhelming majority of our study population (32–34). While we did not find significant drops in diastolic blood pressure among people who are over 71 years, the program still has good reach, with all the population strata captured in these data sets showing at least somewhat lower diastolic blood pressure.

These results show that the program had a positive effect on improving certain dimensions of access for rural East Texas community members to information and support to improve their health outcomes. Through the dissemination of information and instruction on a schedule that was flexible and accessible through a distance learning management system, participants were able to self-pace how the information was consumed within the limitations of week-long modules of content. The dissemination of information *via* CHWs who delivered instruction using language, practical examples and vocabulary that were regionally and culturally sensitive to this specific audience. This observation aligns with similar studies that used CHWs to address health outcomes (diabetes and hypertension management) for specific minority populations (35). Regional and cultural sensitivity matters as instructional methods can be tailored to meet the participants on their intellectual, cultural, and social levels.

This study's findings regarding the effectiveness of CHW-led SMBP interventions in combating hypertension in largely rural East Texas are encouraging. They also indicate the need for further research in this field. Introducing a matched control group would enhance the design, as would the incorporation of multiple pre- and post-test measurements of participant blood pressure. Having additional post-test measures would also make it possible to examine the sustainability of the program's influences on blood pressure levels. A final area of promise for future research is in implementation science. A robust examination of the delivery process from the participants and program staff perspectives could reveal areas of strength in the program and areas that need modification.

This study evaluated the efficacy of a SMBP program among rural community participants. Rural communities exhibit disproportionately poorer health outcomes as compared to their urban counterparts (36). Unfortunately, due to the sampling method, racial and ethnic diversity among participants were not under the control of the researchers. This study only evaluated outcomes based on participant self-reported surveys. It may be helpful to use clinical data to confirm changes in blood pressure as measured in a controlled clinical environment. Additionally, participants were identified and recruited *via* convenience sampling methods. Therefore, participants who agreed to join the programs were particularly motivated to self-enroll into the program in order to address their BP conditions. Hence, if we were to align participants' motivations to change their BP-related health behaviors using the Health Behavior Theoretical Model (37)—the participants in our program would be more likely to be in the "cue to action" phase than potential community members who may have been randomly selected to enroll in the program. Participants' readiness to change their behaviors might disproportionately affect the outcomes for the SMPB program. Finally, since this study was based on one group pre-test and post-test analysis, it is not possible to certain that all the changes that were observed were due to the SMBP program. Further studies using rigorous methods are warranted to expand the effects of CHW-led interventions to control cardiovascular diseases and improve outcomes.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by the University of Texas Health Science Center at Tyler. The patients/participants provided their written informed consent to participate in this study.

Author contributions

KB developed, supervised, and directed the project. CP was involved with planning, coordinating, and delivery of the project. KB and CP validated the data. PM served as principal investigator of the project. MM completed the statistical analysis of the data. KE and YT provided an analysis of the results and discussion sections. All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Julie Ann St. John,
Texas Tech University Health Sciences Center,
United States

REVIEWED BY
Noelle Wiggins,
Independent Researcher, Portland, OR,
United States
Paige Menking,
National Center for Farmworker Health,
United States

*CORRESPONDENCE
Julie Smithwick
✉ julie.smithwick@sc.edu

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"Community health workers bring value and deserve to be valued too:" Key considerations in improving CHW career advancement opportunities

Julie Smithwick[1]*, Jenesha Nance[2], Sarah Covington-Kolb[1], Ashley Rodriguez[3] and Mike Young[1]

[1]Center for Community Health Alignment, The University of South Carolina Arnold School of Public Health, Columbia, SC, United States, [2]Center for Applied Research and Evaluation, The University of South Carolina Arnold School of Public Health, Columbia, SC, United States, [3]Baylor Scott & White Health, Dallas, TX, United States

Introduction: Community health workers (CHWs) are critical members of the public health workforce, who connect the individuals they serve with resources, advocate for communities facing health and racial inequities, and improve the quality of healthcare. However, there are typically limited professional and career building pathways for CHWs, which contribute to low wages and lack of career advancement, further resulting in turnover, attrition, and workforce instability.

Methods: The Center for Community Health Alignment (CCHA), within the Arnold School of Public Health at the University of South Carolina, utilized a mixed-method data collection strategy to provide a more in-depth understanding of this issue and ways that employers, advocates, and CHWs can address it.

Results: Themes across data sources emphasized the importance of retaining skilled and experienced CHWs and educating other health professions about CHWs' critical roles, and reported that doing so will result in decreased attrition professional growth, and improved program quality. CHWs and allies concluded that higher wages, valuing lived experience over formal education, and participation in additional training opportunities should be the primary factors considered for career advancement.

Discussion: Utilizing input from experienced CHWs and CHW allies nationally, this article describes the importance of supporting CHW career advancement, shares best practices, and suggestions for designing strategies that organizations/employers can use to improve CHW career pathways to better support the CHW workforce and reduce attrition.

KEYWORDS

community health worker, workforce development, career pathway, COVID-19, professional development, health equity, leadership, promotores de salud

1. Introduction

There is growing recognition of how community health workers (CHWs) make significant impacts on the health and wellbeing of individuals and communities most affected by inequities (1–8). The American Public Health Association (APHA) definition of a CHW, endorsed by the National Association of CHWs (NACHW), is "a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery (9)."

Several systematic reviews and randomized control trials have found CHWs are associated with improved health outcomes in diabetes (10–13), multiple chronic diseases (14–16), cardiovascular risk reduction (17), hypertension (18), cancer screenings (19, 20), asthma (21), and mental health (22). CHWs help healthcare to accomplish the "Triple Aim" by contributing to improved care experiences and outcomes while maintaining cost-effectiveness (17, 19, 23–28). In addition, CHWs can contribute to enhancing the quality and cultural responsiveness of health and social services and support system-level changes that can have long-lasting impact (29).

While CHWs have been working in the United States for generations, during the recent 20 years, professional institutions have increasingly recognized their role and value in addressing health needs and gaps. In 2002, one of the Institute of Medicine's findings in their "Unequal Treatment" report was "Community Health Workers offer promise as a community-based resource to increase racial and ethnic minorities' access to health care and to serve as a liaison between healthcare providers and the communities they serve (2)." In 2010, the U.S. Department of Labor created a "Standard Occupational Classification" for CHWs, 21-1094. Furthermore, in 2010, the Patient Protection and Affordable Care Act mentioned CHWs 14 times, identified CHWs as a healthcare profession, and called for funding allocation for health promotion among underserved populations (30). During the COVID-19 pandemic, institutions such as the U.S. Centers for Disease Control and Surveillance (CDC) have funded and collaborated with CHWs to provide health outreach and education to hard-hit communities (31). Similarly, in 2022, the American Rescue Plan awarded over 220 million dollars toward community health worker training and capacity building nationwide (32).

As frontline public health workers during the COVID-19 pandemic, CHWs played important roles including communicating COVID-19 prevention and vaccination information to their communities in culturally responsive terms (33), as well as assisting in navigating the overwhelmed healthcare system and connecting clients to virtual medical care and mental health services (34). They also had a critical role in helping people address the myriad of social needs that the pandemic raised. As a result of the increased need in healthcare and public health spaces, coupled with increased evidence of effectiveness, the community health worker workforce is evolving rapidly in terms of professional identification and institutional recognition.

In practice, "CHW" is an umbrella term that encompasses dozens of titles, including peer health advisor, care navigator, outreach worker, community health representative, *promotores*, and more. This multitude of titles is one factor that has affected the potential consolidation of the role into a recognizable and definable profession (35). To address this, the CHW Core Consensus Project (C3 Project), building off the 1998 National Community Health Advisor Study, defined a set of core CHW roles and competencies in 2016 that CHW membership associations, public health institutions, and several states have endorsed (36).

The C3 Project and its predecessors identified CHWs' "connection to the community served" as their "most critical quality" (36). CHW employers prioritize this quality to identify and hire CHWs, more so than levels of formal education or years of employment experience. However, the latter forms the basis for how many institutions and organizations calculate salaries within their compensation and promotion structures. The result is that CHWs often have low salaries and status in the workplace and few opportunities for professional growth without leaving the profession.

The National CHW Common Indicators Project, a multi-institution national initiative to synthesize and improve CHW evaluation, highlights the importance of CHW workforce conditions and career advancement *via* two indicators. Indicator #1 is "CHWs' level of compensation, benefits, and promotion," prioritizing this as an indicator of program quality. Indicator #12 is "Supportive and Reflective Supervision," with CHWs recognizing this as, "...crucial factors affecting the ability of CHWs to grow as professionals, experience job satisfaction, and effectively promote health in their communities." Considering that the improvement of the CHW work environment is reflected in two priority indicators for CHW success, pathways for advancement should be more clearly defined and incorporated into the workflow of organizations that employ CHWs.

The literature on the CHW workforce is growing, yet still somewhat limited. Global literature identifies high attrition rates for CHWs, with contributing factors including low and inconsistent salaries, lack of support, and leaving for better positions (37–45). In a systematic review, Kok et al. found professional growth as a motivating factor for CHWs, and a lack of career advancement options as a demotivating one (46).

In the United States, CHW attrition rates can also be high, with low salaries, low professional status, and lack of opportunities for professional growth driving dissatisfaction (47, 48). Farrar et al. (48) found that addressing barriers to education, training, and promotion led to an improvement in job satisfaction for CHWs. Anabui et al. (47) found that despite the challenges faced in the workplace, most CHWs want to retain their identities, rather than move to other health or helping professions for advancement. They found that clear criteria and opportunities for promotion within their field, including incentives that recognize lived experiences, were motivating for CHWs.

While NACHW, APHA, and the C3 Project have defined CHWs' roles, skills, and qualities, and many state CHW associations have established core competency training and certifications, there is minimal standardized guidance around best practices for hiring or promoting CHWs. Existing guidance emerged from the 1998 National Community Health Advisor (NCHA) Study, which recommended 18 qualities that employers should seek when hiring CHWs. This guidance, although not commonly adopted, could be built upon and shared to promote the enhancement of the CHW workforce. Opportunities for advancement are particularly critical for CHWs, many of whom are themselves from (or closely tied to) populations experiencing inequities, such as members of racial minority groups, immigrants, people with low income, people who were formerly incarcerated, or people in recovery. Lack of mobility may perpetuate their economic and social vulnerabilities.

The purpose of this project was to gather and synthesize first-hand perspectives from CHWs and their allies on this workforce challenge. By collecting CHW input from multiple sources, we describe why it is important to support CHW career advancement, and what employers and advocates can do to develop CHW career tiers or advancement strategies and reduce the threat of losing this vital workforce at a time when the need for their work and expertise has become even more evident.

2. Methods

With support from Johnson & Johnson, in line with their Our Race to Health Equity initiative (49), the Center for Community Health Alignment's Community Health Worker Institute (CHWI) and Center for Applied Research and Evaluation (CARE) at the University of South Carolina Arnold School of Public Health (ASPH) gathered insight from four sources for this project: qualitative data from the South Carolina CHW Ambassadors and CHW Best Practices Council; the National Association of CHWs' (NACHW) 2021 Annual CHW Workforce Survey, a rapid-feedback session of CHWs at the NACHW Unity Conference; and qualitative interviews with six CHW managers or supervisors. The Institutional Review Board at the University of South Carolina approved the study.

2.1. The South Carolina CHW ambassadors and CHW best practices council

A foundational component of CHWI is its engagement of a team of "CHW Ambassadors," experienced CHWs representing a variety of races, ethnicities, geographical locations, populations served, and organizational affiliations. In 2019, the CHWI team selected 10 applicants to be the first cohort of CHW Ambassadors. They contributed to developing plans and strategies for CHW training, capacity building, data collection, and other critical components of CHWI's mission. In addition to the Ambassadors, CHWI invited seven CHW managers or supervisors to be part of a CHW Best Practices Experts Council, whose goal was to determine best practices for implementing and developing CHW programs and growing the CHW workforce in South Carolina effectively. The input from the Best Practices Expert Council on the need for CHW career advancement and a tiered certification structure was the primary impetus for this study. For a year, the council met six times to discuss job descriptions and the factors that should merit increased benefits, recognition, pay, and leadership opportunities for CHWs. The Council discussed various viewpoints until a consensus was reached.

2.2. NACHW's 2021 National CHW workforce survey

The National Association of CHWs (NACHW) invited key influencers, funders, and CHWs leaders to join workgroup sessions toward developing this survey. The workgroup conducted extensive literature review searches, cross-referenced keywords, and identified knowledge gaps regarding the profession. CHWI collaborated with NACHW and its team of CHW advisors to add three additional questions regarding career advancement to the 51-question survey. The survey launched in June 2021, and collected responses through September 2021, ultimately compiling 867 completed surveys (772 in English and 95 in Spanish).

2.3. A rapid feedback session at the 2021 NACHW annual Unity Conference

In July 2021, 160 CHWs and CHW allies attended an invited session at the virtual NACHW Unity Conference, titled "CHWs' Career advancement strategies: Nothing about us without us." Two CHW leaders from the Center for Community Health Alignment conducted the session, which was in English. The facilitators posed open-ended questions about CHW career pathways and collected responses *via* Mentimeter, an online polling platform. In total, 80 individuals responded to four questions posed in a rapid-polling activity. Among attendees that responded to the poll, 70 (87%) identified as CHWs, and 10 (13%) as CHW allies (a supporter, an employer, or a researcher of CHWs). Of CHWs, 35% had been a CHW for more than 5 years, 18% for <1 year, and 36% between 1 and 4 years. Most of the CHWs and allies worked in a healthcare setting (34%) or a community-based organization (33%). Others worked in a public health department (9%), university (9%), or CHW organization or association (8%). Participants did not divulge their geographical locations. The questions were either open-ended or multiple choice and were collected and organized by themes using a deductive approach.

2.4. Individual interviews

Members of the research team conducted six semi-structured interviews with CHWs that are managers or supervisors of other CHWs. The interview guide consisted of several open-ended questions about the CHW career paths at their organizations. Topics included CHW compensation, promotion opportunities, and ways to support future CHWs in career progression. Four CHW managers were from South Carolina organizations, with another from Chicago, Illinois, and one from Dallas, Texas. Three managers worked in community-based settings, while the others worked in healthcare settings. Interviews were conducted *via* the Zoom telecommunication platform. CHWI recruited interviewees based on their knowledge of the CHW profession and experience managing CHW teams. To protect participant privacy, recordings, transcriptions, and analyses were de-identified and stored on a private cloud-based drive. In recognition of their content expertise, participants received a stipend for their participation. The interviews were transcribed using Otter.ai software.

To analyze data, information was coded and analyzed for themes using Microsoft Excel (50, 51). The study team used the constant comparative method (52). As a group, we read through each transcript, noted emergent themes, and compared themes identified in previous transcripts. Furthermore, the study team discussed various viewpoints between team members until a consensus was reached.

3. Results

Several themes emerged across the data sources regarding the need to advance the CHW workforce (the "why") including the importance of retaining skilled CHWs, building respect and appreciation for the profession, and professional growth that

TABLE 1 Top options that CHWs believe should be incorporated into a CHW career path.

Response	English $n = 772$	Spanish $n = 95$	Total $n = 867$
Salary increases	621 (80.4%)	45 (47.4%)	666 (76.8%)
New project/program development	371 (48.1%)	68 (71.6%)	439 (50.6%)
Retention of the CHW title with advancement	398 (51.6%)	36 (37.9%)	434 (50.1%)
Supervisory roles	313 (40.5%)	28 (29.5%)	341 (39.3%)
Authority to lead project teams	255 (33.0%)	46 (48.4%)	301 (34.7%)
Training of non-CHWs	222 (28.8%)	32 (33.7%)	254 (29.3%)

Participants were allowed to select multiple responses.
Source: NACHW Annual Workforce Survey, 2021.

TABLE 2 The top factors that CHWs believe should be valued for a CHW to advance in their career.

Response	English $n = 772$	Spanish $n = 95$	Total $n = 867$
Additional CHW training (continuing education, specialties)	548 (71.0%)	63 (66.3%)	611 (70.5%)
Completing CHW certification	432 (56.0%)	55 (57.9%)	487 (56.2%)
Experience mentoring or training other CHWs	415 (53.8%)	44 (46.3%)	459 (52.9%)
Years providing CHW services	372 (48.2%)	47 (49.5%)	419 (48.3%)
Community member evaluation and feedback	246 (31.9%)	36 (37.9%)	282 (32.5%)
Formal education	183 (23.7%)	20 (21.1%)	203 (23.4%)

Participants were allowed to select multiple responses.
Source: NACHW Annual Workforce Survey, 2021.

TABLE 3 Most frequently appearing codes for responses to open-ended question, "Why is more attention needed on CHW career advancement options?"

Response	#
Respect for the profession	22
Better care for the community	20
CHW retention	17
CHW income	17
Lack of understanding of the CHW role	14
CHWs' unique qualities	10

Source: responses at rapid feedback session during the 2021 NACHW Unity Conference.

will improve program and organizational quality. The themes about the development of opportunities for CHW advancement (the "how") included the importance of salary improvement, making advancement decisions based on lived experience more than formal education, and providing opportunities for additional CHW training and professional development. The responses to the NACHW workforce survey are listed in Tables 1, 2, and Unity Conference session feedback is in Tables 3–5.

3.1. CHW advancement is critical: "*The why*"

3.1.1. Retention

Studies about CHW attrition found that a lack of opportunities for professional growth contributes to turnover rates (47, 48). This is reflected in our findings, first emerging from the CHW Best Practices Council, which identified that the lack of advancement opportunities caused many CHWs to leave the field. They advocated that employers of CHWs and the South Carolina CHW Credentialing Council make CHW retention a high priority by developing tiered levels of certification.

Participants at the Unity Conference agreed, "Having more options for career advancement generally means more people staying in the field, only becoming better at what they do, with the pay they deserve, helping as much people as they can." Another said, "Because the way things are now, we are losing strong CHWs from the field. Those that are most connected to the community are now removed which causes a loss of trust."

3.1.2. Respect for the CHW position

The relationship between CHW advancement and a perceived lack of respect from other professionals emerged at the Unity Conference (Table 3). One CHW stated, "We are treated like housekeeping... a necessary position that is undervalued." Another respondent said, "We are living in poverty, have skills and experience and education, but are trapped, underpaid and underappreciated with no hope of improvement; we are dedicated missionaries." Another wrote, "Because for many companies [the CHW profession] is an unknown field and they do not understand how valuable CHWs are and don't know what to do with us." Yet another stated, "I think people believe it's just volunteer work."

The interviewed managers agreed. One manager stated, "Yeah, I just think the... [profession]... is brand new. Like, we are learning about all the benefits that our work offers to the community. … We need to create awareness to the funders about the value that we provide to the community and to the medical services and the government, how much money they saved… I think like doing research, like a study of the return on investment… real numbers that you can show to the funders, so they can see the benefit of our profession." Another suggested that awareness building is an important role for CHW allies, "Continue to work and push

TABLE 4 Benefits CHWs believe should be available as they advance in their careers, in descending order.

Response	#	$n = 75$
More pay	68	90.7%
More professional development	65	86.7%
Management opportunities	47	62.7%
Opportunity to supervise	43	57.3%
Freedom to operate more independently	37	49.3%
Speaking opportunities	36	48.0%
More responsibilities	25	33.3%

Source: survey distributed at rapid feedback session during the 2021 NACHW Unity Conference.

work with organizations, to develop Community Health Worker programs, and help them to understand the role of Community Health Workers and why they're important, continue to advocate for Community Health Worker pay." Educating other professionals and team members about the role of CHWs will help showcase their value in the workplace, further incentivizing them to stay and grow.

3.1.3. Professional growth and quality improvement

The interviewees also mentioned that CHWs' professional growth will ultimately result in improved services to patients and participants. "We all want to get better all the time and, and make more money, and just think that you are growing, that you are learning, and that you are growing in your profession. Just like it is good for us and it motivates you to have like a better position, a better salary. I think that's important for everybody." Another interviewee stated, "Oh, it gives them something to strive for, it gives them something to look forward to, you know, I'm saying it allows them to take the initiative to improve themselves, in professional development."

3.2. Factors to consider when developing CHW advancement pathways: *"The how"*

3.2.1. Salary

Across data sources, CHWs identified "salary increases" as the most important factor to consider in advancement opportunities. "Higher salary" was the most frequently mentioned priority for CHWs in both the NACHW Workforce Survey (Table 1) and the Unity Conference session (Table 4) when asked what should be incorporated into advancement pathways. One conference attendee commented, "CHWs are often one paycheck away from needing the services we provide."

The CHW managers are aware of the impact of low salaries on their CHWs; one said, "It's just I have been advocating for my team to get a better salary, but it is very hard for us to get the resources. … I really would like to have more for my Community Health Workers because they work so hard. And they really deserve to have a better salary." However, they also deal with the challenges of finding funding sources for those salaries. One manager said, "You know how it works when you work with grants, you have this person for 1 year and she learned so many things, she's gained so many skills, and then she has to leave because I don't have any more funds." Two CHW managers suggested institutional funds or insurance payments be aligned with CHW services. One suggested, "Oh, that's the biggest challenge for me that I would really like... maybe the hospitals to take over these programs and say, 'okay, I'm going to pay you like, to permanently to do the work.'" Another mentioned, "[A] patient came in, and we assisted them with food insecurity, boom, that should be a code. Right? That should be a compensation point."

TABLE 5 Most frequently appearing codes for responses to open-ended question, "What factors need to be considered to move CHWs from one level to the next?"

Response	#
Experience	27
Training	24
Education	20
Lived experience/community connection	18
Organizational support	8

Source: responses at rapid feedback session during the 2021 NACHW Unity Conference.

3.2.2. Valuing lived experience above formal education

At the Unity conference session, many responses to the question, "What factors should be considered to move CHWs from one level to the next?" were related to experience as CHWs and lived experience as a member of the communities served (Table 5). Answers to the question included, "Respecting experience and not just the letters after your name," and "Experience in the field and the resources we bring... how we are respected in the community." One CHW said, "Because CHW's speak in everyday people's language! That's why what we do works!"

Multiple interviewed CHW managers agreed they would hire or promote other CHWs based on lived experience. One manager stated, "So I struggle with that sometimes, because I sometimes do get caught in okay, what kind of education do they have? … But then I had to, I had to catch myself sometimes. That's not what is at the heart of a Community Health Worker. It's the community. It's the person. Its, you know, what role have they played in their community?" When asked what factors are important in promoting CHWs, another CHW manager stated that, "experience dealing with the population that we're trying to target… and being able to meet those patients where they're at," was important. Another manager said, "I found out some of the ones, you know, that that didn't have that that degree or, or may not always have had a medical experience are the best ones."

The value of lived experience and community connections contrasts with many employing institutions' emphasis on formal education and credentials. In the NACHW workforce survey, when asked about barriers to their success as CHWs, 25% of CHWs identified higher-level education and 21% "other credentials" (53).

TABLE 6 Baylor Scott & White Health CHW positions.

Position	General description
CHW in-training	Embedded community member that has the desired experience and knowledge of their community but does not necessarily have the required Texas Department of Health Services CHW certification; they are required to complete certification training within 1 year of employment.
CHW I	Experienced CHW, with current DSHS certification
CHW II	Experienced CHW, with current DSHS certification, that may have taken a team lead role and/or have applicable experience
CHW supervisor	Experienced, "veteran" CHW, with current certification, who has the capacity to manage a team
CHW manager	Experienced CHW that supports multiple care settings, may directly oversee CHW staff, and may serve at a system level in a project management capacity to support and drive CHW initiatives

TABLE 7 South Carolina CHW tiers.

CHW position	General description
Certified community health worker (CCHW)	• Successful completion of a SCCHWCC approved CHW Core Competency Curriculum: 80 h classroom, 80 h practicum, SCCHW Examination • Registering on the South Carolina Community Health Worker Association (SCCHWA) CHW Portal
Certified community health worker II (CCHW II)	• Minimum of 4 years working the field • Bi-Annual Recertification (24 h every 2 years) • Certification of Completion of a minimum of 4 CHW Specialty Tracks • Demonstration of at least 1 year in CHW leadership (CHW ambassador, SCCHWA board, active involvement in SCCHWA workgroup, active involvement in CHW regional or national committee or initiative, CHW Preceptor, CHW supervisor, CHW program leadership or program development at organizational level) • Updated profile on the SCCHWA CHW Portal • Application submission
Certified community health worker III (CCHW III)	• Minimum of 8 years working the field • Bi-Annual Recertification (24 h every 2 years) • Certification of Completion of a minimum of 6 CHW Specialty Tracks • Demonstration of at least 2 years in CHW leadership (CHW ambassador, SCCHWA board, active involvement in SCCHWA workgroup, active involvement in CHW regional or national committee or initiative, CHW Preceptor, CHW supervisor, CHW program leadership or program development at organizational level) • Updated profile on the SCCHWA CHW Portal • Application submission

CHWs have deep knowledge and experience in the community; determining how to place value on this quality in an institutional setting is critical.

3.2.3. CHW training and professional development

While most respondents did not prioritize associating CHW advancement with formal education, there is a theme of wanting CHW training, professional development, and certification as means of advancing. The CHW Best Practices Council recommended that additional CHW-focused education and experience should help move a CHW from one tier to the next.

The national survey respondents agreed; CHWs ranked "additional CHW training" as the top factor to be valued in their career paths (Table 2). This was followed by CHW certification, then experience mentoring other CHWs. An interviewee also agreed, suggesting training as a method of supporting CHW advancement, "I would say continue to provide educational pathways for Community Health Workers, professional development." Another interviewee suggested that organizations should, "…assess company needs and provide training and education."

4. Discussion

These findings show that more effective and equitable career pathways for CHWs would provide motivation for CHWs to remain in the workforce, promote retention, recognize effective work and leadership, and contribute to organizational quality improvement. CHW career advancement pathways should recognize the unique contributions of CHWs to health improvement, take into consideration the best practices offered by the workforce, and support CHWs in addressing the challenges and barriers that exist.

In the past few years, a growing number of institutions and organizations have realized the need to hire and integrate CHWs into their work. However, the CHW field faces multiple threats that can result in attrition and burnout and put the workforce and employers at risk of not being able to meet the growing demand. CHWs have reported feeling undervalued, underpaid, and not respected. By not providing opportunities for CHWs to grow in their field, organizations risk losing those CHWs with the most experience, as opposed to building on that expertise to support newer CHWs.

4.1. Challenges to be addressed

The barrier that was most frequently mentioned by CHWs and CHW allies was funding, both in terms of having enough funding to offer higher salaries and having sustainable funding so that positions are not dependent on grants and other one-time funding sources. Due to the value of CHWs' lived experience and connection to the populations they serve, CHWs can be at high risk of poverty, which makes offering livable wages essential. In addition, time limited and insufficient compensation pose substantial risks to the CHW workforce. Our findings suggest that having more sustainable and equitable funding will facilitate the retention of CHWs.

Another major challenge pertains to human resource systems and processes placing value on higher education and formal degrees rather than lived experience. Foremost, higher education can be financially cumbersome for CHWs, many of whom hail from marginalized populations. Similarly, CHW managers, CHWs, and the C3 Project agree that lived experience is a core quality of a CHW. Therefore, loosening requirements surrounding formal education and valuing lived experience can assist in finding and promoting the right individuals for CHW positions. It can also assist in building financial equity for CHWs because they will have opportunities for advancement without incurring additional debt. Further emphasis needs to be placed on understanding and dismantling systemic racism within organizations due to the part that it plays in maintaining hierarchical leadership that keeps those with privilege in power. The role of privilege and power dynamics needs to be recognized and addressed in order to determine paths to leadership that are more equitable, open, and transparent.

Finally, there is a need for more awareness of CHW's roles and contributions to public health and healthcare. Many stated that employers such as hospitals and state or federal agencies lack awareness of the roles, qualities, and importance of CHWs. Similarly, community members may not understand the role of a CHW. Developing strong communication plans that include training employers and marketing to the public can assist in raising awareness of the CHW profession, creating more respect for the CHW role and scope, helping keep experienced CHWs in the workforce, and incentivizing others to join the field.

4.2. Designing CHW advancement pathways

Almost all CHWs and allies reported that most CHWs want to stay in and be able to progress within their field, as opposed to having to leave the CHW workforce to pursue additional opportunities. However, many CHWs stated that employers will not allow them to progress without adopting a new title or professional identity. Developing a tiered CHW advancement framework, such as the ones in the case examples included, can guide employers and advocates in their efforts to promote and retain CHWs. Advancement factors can include additional training, professional development, certifications, mentorship of other CHWs, years in the CHW field, and the quality of their work. CHWs strongly favor their profession's own training, certification, and experience as factors for advancement, more than formal education or external qualifications. Upon advancing, CHWs should be granted opportunities to participate in leadership roles, mentorship, program design, and advocacy.

4.3. Examples

Later are two examples of organizations that have created and implemented CHW career advancement pathways, with strong and intentional input from CHWs.

4.3.1. CHW tiered system at Baylor Scott & White Health

Baylor Scott & White Health (BSWH), the largest not-for-profit healthcare system in Texas and one of the largest in the United States, employs CHWs to help patients navigate an increasingly complex healthcare system, facilitate self-management of chronic diseases, and connect patients to primary care medical homes. BSWH CHWs act as peers, navigators, advocates, educators, and promoters of improving outcomes and quality of life for the patients they serve.

In 2007, BSWH hired one CHW as a diabetes educator. In 2009, the team expanded to four CHWs through the Diabetes Equity Project, and in 2011, BSWH created new positions, marking the start of BSWH's current CHW career ladder efforts. Between 2011 and 2014, the integration of CHWs expanded even more through various grant and funding opportunities.

As the system developed more CHW programs, CHW supervisors recognized the need for a systemic approach to CHW support that could bridge the programs. They created the CHW Development Council to meet this need. This Council utilized key data derived from annual workforce feedback surveys at the BSWH CHW Summit and the Texas core competencies for public health professionals to build a career ladder. Rather than encouraging BSWH CHWs to pursue growth through other career ladders such as becoming social workers or other healthcare professionals, they determined it was more effective and supportive to build a CHW career ladder that respects the CHWs' passion and path, thus allowing BSWH to retain talented and invaluable CHWs at all levels for the last decade.

The CHW Development Council developed the advancement levels in Table 6 and provided the levels to supervisors as a framework they can use to help grow and retain their CHWs. Currently, BSWH employs over 120 CHWs.

4.3.2. South Carolina CHW tiers

As previously mentioned, the South Carolina CHW Best Practices Council (BPC) identified CHW career advancement as a high priority for the CHW workforce in South Carolina. The South Carolina CHW Credentialing Council (SCCHWCC), which is supported by the South Carolina Community Health Worker Association, is the statewide approving body for CHW training programs, certification, and continuing education. The SCCHWCC is composed of at least 51% CHWs, along with representatives from the state Medicaid institution, the state public health department, AHEC, higher education, and a health insurance entity.

The BPC worked to draft examples of tiered CHW job descriptions, based on the different requirements for the position. The Council also recommended that, statewide, there should be multiple tiers of CHW certification, and that additional CHW-focused education and experience should be what help move a CHW from one tier to the next.

Based on the work initiated by the BPC, CHWCC made enhancements to the CHW credentialing process, creating a three-tiered system for certified CHWs. The Credentialing Council drafted these tiers and reviewed them multiple times with the BPC. In April 2022, the three-tiered certification in Table 7 was approved and it was launched in January 2023. In the future, efforts will be made to educate employers on the certification tiers, to encourage them to adopt them, along with appropriate advancement in salaries and opportunities for CHWs.

4.4. Limitations

Limitations of this study include a lack of consistency across data sources; the questions were similar, but not identical. To address this, the team gathered data from multiple sources to make sure the themes were accurate and consistent.

Respondents of the national CHW survey may have been impacted by survey fatigue bias, due to the length of the questionnaire. In addition, the interviews and Unity Conference sessions were in English. Aligning interview data of Spanish speakers with the survey data could have brought more insight to researchers around the differences between how English and Spanish-speaking CHWs are employed and promoted. Further research can be conducted in various languages and with CHWs from different backgrounds to determine if there are nuances in factors affecting CHW advancement.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by University of South Carolina Institutional Review Board. The NACHW survey and conference poll were anonymous, and did not require written consent. Individual interview participants provided their verbal consent to participate in this study.

Author contributions

JS and MY designed the study and led data collection. JN and SC-K contributed to analyzing the data and preparing the manuscript. AR reviewed for relevancy to the field and provided case study input. All authors contributed to the article and approved the submitted version.

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Conflict of interest

AR was employed by Baylor Scott & White Health.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix

CHW interview guide

Do I have permission to record this interview?

Thank you for taking the time to interview with me today. First, I'm going to get some information about you and your role within your organization.

1. Tell me a little about yourself and your work at your organization.
    a. How long have you been a CHW? How long have you worked at your organization?
    b. About how many CHWs does your organization employ?
    c. How many do you directly supervise?
    d. What are the funding sources for your CHWs pay?
2. Next, we're going to discuss the career path for CHWs in your organization. When I say career path, I mean how people grow or advance in their job, such as opportunities for promotions or pay raises. Does your organization have a career ladder for CHWs? If so, tell me about them.
    a. Does your organization have education or experience requirements to promote CHWs?
    b. What barriers or challenges have you faced when developing a career ladder? How did you address these barriers?
    c. Why do you think having a career ladder is important?
    d. What factors should be considered to move CHWs from 1 level to the next?
    e. What qualities/personality traits do you look for when hiring or promoting a CHW?
3. What does compensation look like for CHWs at your organization? What is the lowest and highest salary range?
    a. What types of benefits do your CHWs receive?
    b. Any other benefits (mileage, per diem, etc)
    c. What about the CHW model at your organization do you think is unique?
4. If you had the opportunity to change anything about the CHW profession, what would it be?
    a. Have you heard anything from former CHWs about why they left the position?
5. In your opinion, how can we better support CHWs in advancing their careers?
6. What else can you share with me that could be helpful as we try to work on this?

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EDITED BY
Lily K. Lee,
Loma Linda University, United States

REVIEWED BY
Isadore Leslie Rubin,
Morehouse School of Medicine, United States
Julie Ann St. John,
Texas Tech University Health Sciences Center, United States
Kylie Jeffery,
University of Texas Health Center,
United States, in collaboration with reviewer JS

*CORRESPONDENCE
Samantha Sabo
✉ samantha.sabo@nau.edu

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Community Health Representative Workforce: Integration across systems and teams to address the social determinants of indigenous health and wellbeing

Samantha Sabo[1]*, Louisa O'Meara[1], Janet Yellowhair[1], Joyce Hamilton[2], J. T. Neva Nashio[3], Brook Bender[4], Fernando Flores Jr.[5], Marianne Bennett[6], Rema Metts[7], Isabella Denton[8] and Kim Russell[8]

[1]Center for Health Equity Research, Northern Arizona University, Flagstaff, AZ, United States, [2]Hopi Tribe, Hotevilla, AZ, United States, [3]White Mountain Apache Tribe, Whiteriver, AZ, United States, [4]Hualapai Tribe, Peach Springs, AZ, United States, [5]Colorado River Indian Tribe, Parker, AZ, United States, [6]Salt River Pima Maricopa Indian Community, Scottsdale, AZ, United States, [7]Gila River Health Care, Sacaton, AZ, United States, [8]Arizona Advisory Council on Indian Health Care, Phoenix, AZ, United States

Tribally employed, Community Health Representatives (CHRs) serving Indigenous and American Indian and Alaskan Native (AIAN) peoples are culturally and linguistically embedded community leaders, with the unique ability to serve as the link and intermediary between community members and systems. Unique to the CHR workforce scope of practice is the expectation for high level integration within the medical and social service care team. This explicit role outlined in the scope of work sets an expectation for both CHR and care teams to deliver integrated patient, family, and systems level care coordination and case management. This paper aims to build from our previous manuscript published in Volume 1 of the special issue *Community Health Workers Practice from Recruitment to Integration*. In that Volume, we explored through a Community Case Study CHR Managers' perspectives on the challenges and opportunities for full CHR integration into health systems and teams serving AIAN. In this paper, we offer new information about the current CHR and CHR Managers' involvements and perceived level of integration within health care teams and the broader public health systems addressing the social and structural determinants of health. We approach this topic considering the COVID-19 pandemic and how CHRs and CHR Programs were included and not included in tribal pandemic response efforts.

KEYWORDS

Community Health Representatives, health systems, patient centered approaches, COVID-19, primary care, indigenous health and wellbeing, Community Health Workers

1. Introduction

Tribally employed, Community Health Representatives (CHRs) serving Indigenous and American Indian and Alaskan Native (AIAN) peoples are culturally and linguistically embedded community leaders, with the unique ability to serve as the link and intermediary between community members and systems (1). Since 2015, community and academic partners from the Northern Arizona University Center for Health Equity Research

(NAU-CHER), the Arizona Advisory Council on Indian Health Care (AACIHC), and 19 tribal Community Health Representative programs have come together to document CHR workforce roles and competencies (1, 2). Together, we have confirmed high levels of cultural, traditional, and linguistic experiences and knowledge held by the Arizona CHR workforce and its leadership, and the extant para-professional training they possess to meet the unique needs of AIAN patients and tribal and healthcare systems and teams. Unique to the CHR scope of practice, CHRs and their respective programs engage in case management and care coordination, including patient direct care, service coordination, patient navigation, and advocacy (3). These evidence-based characteristics are critical to high-functioning care teams, improved patient outcomes, and lower healthcare costs (4–6). Also unique to the CHR workforce scope of practice is the expectation for high level integration within the medical and social service care team (1, 7). This explicit role outlined in the scope of work sets an expectation for both CHR and care teams to deliver integrated patient, family, and systems level care coordination and case management. As a member of the care team, CHRs are expected to assist in the development of patient care plans, serving as both patient advocate and patient navigator to ensure continuity, completion, and acceptability of care. Yet, inherent challenges remain to optimize CHR integration, specifically in the areas of care team role delineation, communication, and coordination between care team providers (8, 9).

In Arizona, licensed healthcare providers, including those serving in Indian Health Service (IHS) and tribal health systems, consider CHRs to be valuable members of health teams (10). Moreover, Arizona Medicaid contracted health plans, 30% of whose members identify as Indigenous and AIAN, are highly motivated to integrate the broader Community Health Worker (CHW) workforce, inclusive of CHRs, within systems and teams (10). This is motivated in part by reforms in healthcare financing in the US, incentivizing a shift toward a value-based reimbursement structure that rewards evidence of favorable medical and social outcomes (11). Further evidence of the commitment and transition to patient centered coordinated care models to best serve Indigenous and AIAN populations, is observed through efforts by the Arizona Medicaid, known as the Arizona Health Care Cost Containment System (AHCCCS), to establish the American Indian Medical Home (AIMH) Program (12). Established in 2017, the AIMH Program, the first of its kind in the nation, was brought to fruition through a robust partnership between AHCCCS and tribal leadership in Arizona. The AIMH Program supports primary care case management, diabetes education, and care coordination for enrolled members. AIMH is intended to address health disparities between AIAN and other populations in Arizona by enhancing case management and care coordination. The AIMH is consistent with national moves of the IHS to adopt the Patient Centered Medical Home model, which IHS launched nationally in 2009 (13) and is currently operating in several tribally administered health systems across Arizona and beyond (14). In 2018, American Indian health policy entities in collaboration with Arizona Tribes advocated for the inclusion of CHRs as AIMH care team members. Despite a clearly defined CHR scope of practice within the health systems and primary care team, CHRs were not included as a designated reimbursable AIMH care team member by AHCCCS.

Most notable, is how tribally employed CHRs have been at the forefront of tribal communities' response to the COVID-19 pandemic. This experience illuminated both the greatest of potential and sorely missed opportunities for the entire CHW workforce, and specifically CHRs to be integrated into COVID-19 prevention and care systems to address serious health inequities laid bare by the "Merciless Monster" as the former Navajo Nation CHR Program Manager Mae-Gilene Begay MSW, once said (15). Throughout the pandemic and because of their trusted relationships and familiarity with the social and physical landscape of tribal lands and citizens, CHRs were invited to support public health surveillance, contact tracing, and case management of COVID-19 patients. CHRs provided critical health education and messaging around COVID-19 prevention and vaccination (7). Response efforts of Navajo Nation, White Mountain Apache Tribe and Hopi Tribe were nationally recognized for their effective, community-based infection prevention and mitigation strategies (15–18).

This paper is rooted in these experiences gained over the course of the pandemic, and knowledge and action related to growing evidence and policy opportunities in Arizona to implement best practices for integration of CHRs into systems and teams. Specifically, this paper aims to build from our previous manuscript published in Volume 1 of the special issue, *Community Health Workers Practice from Recruitment to Integration*. In that Volume, we explored through a Community Case Study CHR Managers' perspectives on the challenges and opportunities for full CHR integration into health systems and teams serving AIAN. In this paper, we offer new information about the current CHR and CHR Managers' involvements and perceived level of integration within health care teams and the broader public health systems addressing the social and structural determinants of health. We approach this topic considering the COVID-19 pandemic and how CHRs and CHR Programs were included and not included in tribal pandemic response efforts.

2. Context

Through a highly participatory process with major entities representing the interests of Indigenous and AIAN people throughout Arizona, and through funding from the CDC Community Health Workers for COVID Response and Resilient Communities (CCR), we launched the Community Health Representative Workforce Integration in Tribal Health Systems to Address COVID-19 (CHRs WITH uS!) project.

CHRs WITH uS! is a collaborative initiative, and one of just eight tribes, tribal organizations, or health service providers to tribes funded among the 69 organizations funded by the CDC CCR mechanism nationally. CHRs WITH uS! focuses on increasing the capacity of CHR Programs and their integration within the Indian Health Service and tribal health and care systems serving rural, Indigenous and AIAN citizens of Arizona. CHRs WITH uS! is led by the Arizona Advisory Council on Indian Health Care, in collaboration with a consortium of seven tribally operated CHR programs including: Cocopah Indian Tribe, Colorado River Indian Tribes, Gila River Health Care, Hopi Tribe, Hualapai Tribe, Salt River Pima-Maricopa Indian Community and White Mountain

Apache Tribe with technical assistance and evaluation provided by Northern Arizona University, Center for Health Equity Research. In this community case study, we offer new insights afforded through the CCR grant held by CHR Programs regarding the roles they played in the COVID-19 pandemic response efforts; and current attitudes, beliefs and behaviors related to their workforce and programmatic integration within public health and health care systems and teams.

3. Key programmatic elements

3.1. CHRs WITH uS! workforce assessment

Through highly participatory methods, a CHRs WITH uS! Workforce Assessment was developed to establish a CHR workforce baseline and enable evidence informed strategic planning and policy over time. In alignment with community based participatory evaluation (CBPE) and best practices in Indigenous evaluation and CHW engagement practices, the assessment incorporated mixed methods including a survey and structured conversational interviews. The survey is designed as an annual, online cross-sectional survey of CHRs and CHR managers of Arizona. Survey domains include: (1) Demographics (race and ethnicity, age, gender, employment history, education, licensure and certification, income); (2) Roles, competencies and activities; (3) Referrals and Care Coordination (tribal health programs, health care systems); (4) Professional Development and Training; (5) Integration into primary care teams (roles, team members, perceived integration, communication); (6) Levels of collaboration with tribal Health Programs and; (7) COVID-19 Response (emergency preparedness, testing, tracing, vaccine roll out). The workforce survey was developed, piloted and revised in collaboration with the CHRs WITH uS! partnership and the Arizona State University CDC CCR 2110 National Evaluation team. Survey items are adapted from several sources including previous CHR workforce surveys conducted in Arizona (7), the 2021 AzCHOW CHW Workforce Integration Readiness Assessment (19), the 2020 Louisiana CHW Workforce Study (20), CHW Core Consensus Project (21) and the CHW Common Indicators Project (22). Here we present preliminary descriptive analysis using SPSS software for quantitative analysis.

The survey is coupled with a semi-structured qualitative interview conducted in a conversational style—in person or *via* Zoom—with CHR managers. The interview guide explores project implementation, program function, health and human service system integration, engagement with process and outcomes evaluation, and CHR Program involvement with COVID-19 response efforts. Detailed notes were taken during interviews, and in the case of Zoom meetings, interviews were recorded and transcribed in summary form. Notes were then revised for clarity and flow and sent back to the interviewee for review and approval. All interview transcripts were entered into Atlas.ti Qualitative Analysis Software and coded according to question domain through a rapid analysis method.

Again, in line with tenants of CBPE, best practices in Indigenous evaluation and CHW engagement practices, results were shared back with CHRs and managers through mini reports, presentations, and popular education techniques. Through these processes, assessment results were interpreted and clarified, while recommendations and strategic planning were explored and operationalized.

3.2. Participant demographics and professional training

A total of 48 CHRs and 13 CHR managers/supervisors completed the survey. Respondents represented 10 different CHR Programs or urban Indian health centers operating in Arizona (Table 1). Nearly 80% of CHRs and CHR managers identify as American Indian or Alaska Native women. CHRs and managers were similar in average age of 46 and 45 years old, respectively, both representing a large range in age. In terms of time in current position, CHRs averaged 7.5 years, with a range of being newly hired as a CHR with <1 year to CHRs with more than 40 years of experience. This is compared to more than half of CHR managers who reported being in their position for 5 years or less. Nearly all surveyed CHRs work in full-time positions, with more than half reporting a salary of $35,000 or less per year. CHR managers reported higher salaries, more than half earning over $50,000 annually. Nearly three-quarters of surveyed CHRs (73%) and CHR Managers (69%) reported having attended some college or having achieved a 2-year associate degree. Professional development and preparation are a cornerstone of CHR Programs, written into their job descriptions, therefore the workforce was asked about which licensures or certifications they hold. Choosing from a dropdown list of options, as well as writing in any others that were not listed, most CHRs and managers are First Aid/Basic Life Support (77% among both groups) and CPR (71 and 62%, respectively) certified. Nearly half of all CHR respondents are Certified Nursing Assistants (CNA). Training not specific to, but important to mention, held by this workforce included Respiratory Therapy Tech, Dialysis Patient Care Tech, Phlebotomist, Dietary Manager, and Certified Lactation Counselor. Some CHR managers also had specialty training including RN and AADE Diabetes Educator certification. Such professional certification and cross training add value to the CHR programs and make them highly desirable in remote and rural regions in which they work.

3.3. CHR roles and activities

Although not the focus of this paper, we want to highlight that CHR roles and activities were also assessed. CHR roles and scope are set by the Indian Health Services, *Indian Health Manual*, which defines the standards of practice for the entire workforce (23). Additionally, findings from previous assessments with the Arizona CHR workforce (7, 24) have confirmed that CHRs' scope of practice is aligned with the Community Health Worker Core Roles as identified by the CHW Core Consensus Project (21). Presented with a list of 19 roles and or activities based on both sources, the current workforce survey confirmed again that Arizona CHRs and managers engage or support the full scope of practice. In this assessment, more than 80% of CHRs indicated that

TABLE 1 CHR workforce survey participant demographics.

	CHR ($N = 48$)	CHR managers ($N = 13$)	Total ($N = 61$)
Age, mean years, (range)	45.7 (20–73)	45.3 (33–76)	45.6 (20–73)
Gender			
Female	81.3% (39)	84.6% (11)	80% (50)
Male	16.7% (8)	15.4% (2)	16.4% (10)
Non-binary	2.1% (1)	0	1.6% (1)
Time in position, mean years, (range)	7.5 years (<1 to >42)	5.3 (<1 to >13)	7.025 (<1 to >42)
Race and ethnicity			
American Indian or Alaska Native	95.9% (47)	84.6% (11)	87.9% (58)
White	2% (1)	38.5% (5)	9.1% (6)
Black/African American	–	7.7% (1)	1.5% (1)
Hispanic or Latino	6.3% (3)	23.1% (3)	9.8% (6)
Tribal member	93.8% (45)	76.9% (10)	90.2% (55)
Annual salary			
\$10,000–25,000	19% (9)	0 (0)	14.8% (9)
\$25,000–35,000	40% (19)	8% (1)	32.8% (20)
\$35,000–50,000	25% (12)	23% (3)	24.6% (15)
\$50,000–75,000	0 (0)	54% (7)	11.5% (7)
\$75,000+	0 (0)	8% (1)	1.6% (1)
Prefer not to answer	17% (8)	8% (1)	14.8% (9)
Full time employment status	98% (47)	100% (13)	98.4% (60)
Education			
Less than high school degree	6.3% (3)	0 (0)	4.9% (3)
High school graduate or GED	20.8% (10)	0 (0)	16.4% (10)
Some college, but no degree	37.5% (18)	53.8% (7)	41% (25)
Associates degree (2-year)	35.4% (17)	15.4% (2)	31.1% (19)
Bachelors degree (4-year)	0 (0)	30.8% (4)	6.6% (4)
Licensure/certification			N = 61
First aid/basic life support	77.1% (37)	77% (10)	77.0% (47)
CPR Certification	70.8% (34)	62% (8)	68.9% (42)
Certified Nursing Assistant	47.9% (23)	23% (3)	42.6% (26)
Certified Medical Assistant	17% (8)	15% (2)	13.1% (8)
Family Spirit Certification	14.6% (7)	23% (3)	16.4% (10)
CHW voluntary certification	8.3% (4)	0 (0)	6.6% (4)
Diabetes Community Care Coordinator	4.3% (2)	0 (0)	3.3% (2)
Registered nurse	2% (1)	8% (1)	1.3% (2)
** AADE Diabetes Educator (manager)	4.2% (2)	7.7% (1)	
**Licensed Practical Nurse (LPN)	0 (0)	14.4% (2)	
**Registered Dietician (RD)	0 (0)	7.7% (1)	

**Write-in response.

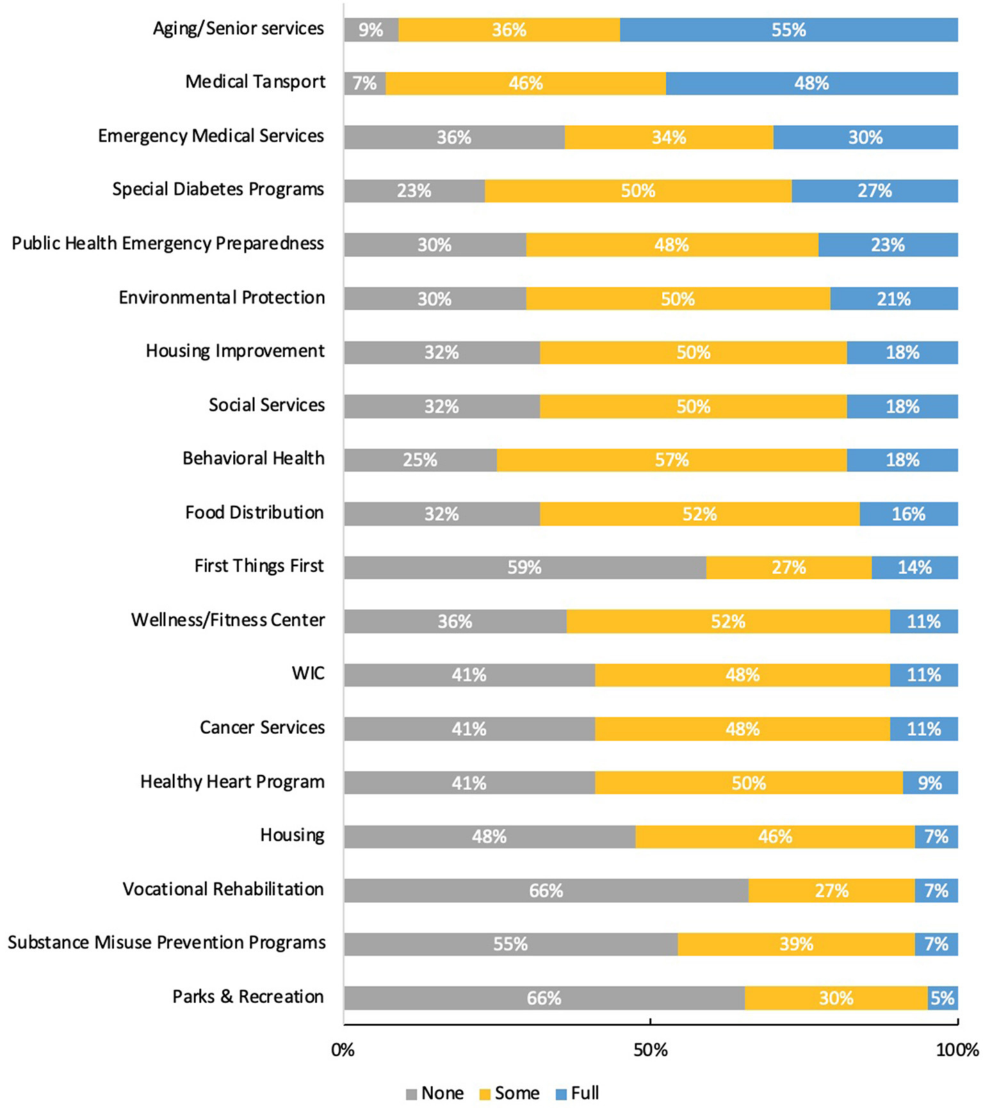

FIGURE 1
Collaboration among CHRs and public health services by type and level ($N = 44$ CHRs).

their work includes case find/screen, health education, individual and community outreach, medical appointments (scheduling, maintaining, etc.), and promoting healthy lifestyles (e.g., nutrition, exercise, etc.). According to responses from CHR Managers, a large part of their work is community-focused, including advocating for patients or community (85%), individual and community outreach (92%), and promoting healthy lifestyles (100%).

3.4. CHR collaboration with public health systems

Fundamental to enacting the core CHR roles and competencies of cultural mediation, social support, advocacy and health education is the level of connection a CHR has to services and programs which address the social determinants of health (SDoH). We assessed the level (*none*, *some* or *full*) at which CHRs and managers collaborated with public health services available in their area and or operated by their Tribe or tribal organization. Levels are defined as no interaction (none), some interaction (send/receive referrals, occasional communication), and full collaboration (frequent communication, referrals, joint projects). Here we present CHR responses only (Figure 1). CHRs' experiences varied, with approximately half of all CHRs reporting *some* collaborative relationship with the following programs: medical transportation, the IHS-coordinated Special Diabetes Program for Indians (SDPI), housing, environmental protection, social services, behavioral health, and food distribution. Given the reverence and historical commitment of the national CHR Program to community elders, more than half of all programs reported having a *full* collaboration with aging and senior service programs operated in their communities. Transportation is a major structural determinant of health for many community members living on

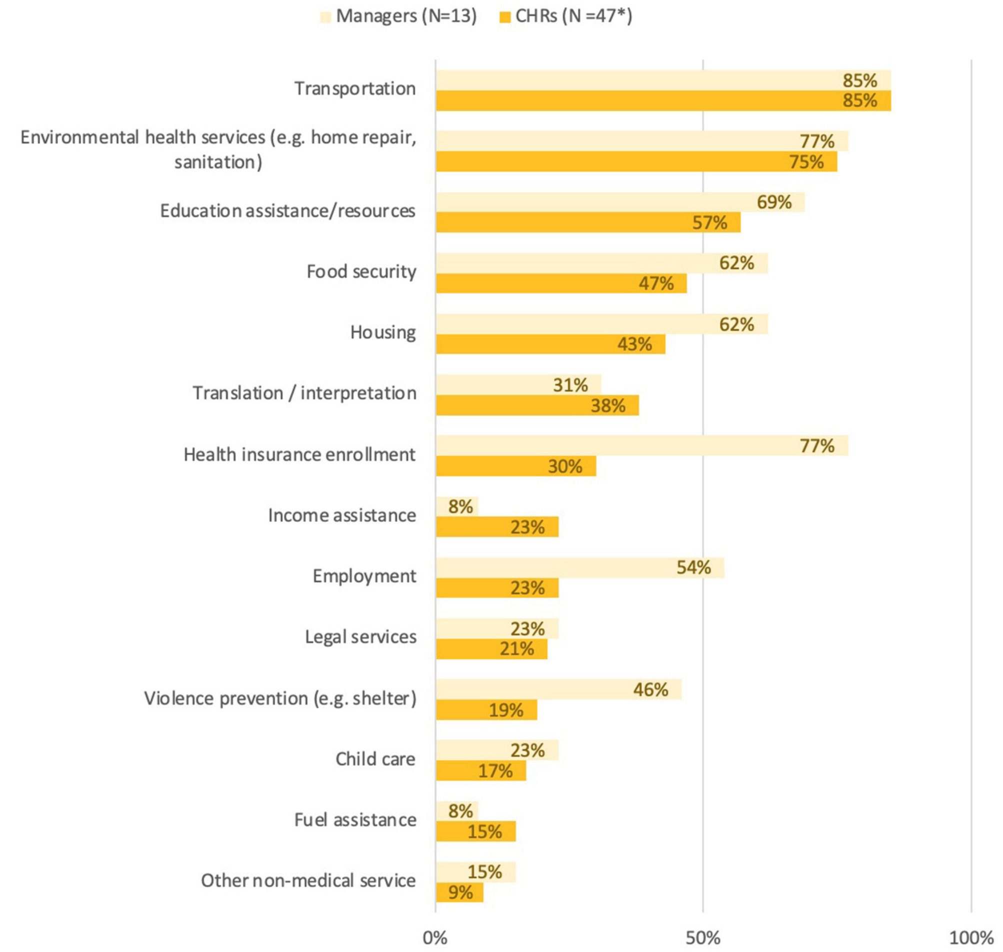

FIGURE 2
CHR referral categories.

tribal homelands, which is reflected in the high level of reported *full* collaboration with medical transport services operated by the Tribe and IHS. Although the assessment results highlighted several opportunities for new partnerships, especially with vocational rehabilitation, parks and recreation and the First Things First initiative (a state-run program supporting parents and children aged 0–5 years), we recognize that not all of these types of services are available to all survey respondents, and therefore may have been reported as *none*.

3.5. CHR social determinants of health referrals

Building from the level and type of collaborations that CHRs have with other community programs—we assessed how CHRs and managers address the social and structural determinants of health by connecting clients to services through referrals. The referral service categories included in the survey were generated through free listing with managers and CHRs of the known programs and services in their region, and further adapted from a recent Community Health Worker Workforce Study (20). Among both CHRs and CHR manager respondents, the two most common referral categories were transportation and environmental health services. Environmental health services are a broad category that was defined and interpreted as including home repair programs that address access to electricity, potable water, and sanitation services, as well as programs that address home safety and disability access such as installment of wheelchair accessible ramps. The largest differences (>20% margin) between CHRs' and managers' reported referral categories were found in health insurance enrollment, employment services, and violence prevention—with a significantly greater percentage of managers perceiving CHRs connecting clients to these three services. These data suggest programs are connecting community members to services critical to addressing the major SDoH of education, food, housing and language and interpretation services (Figure 2).

3.6. CHR program involvement in COVID-19 response

Next, we explore how CHR Programs were engaged in COVID-19 pandemic response efforts (Figure 3). We intentionally offer

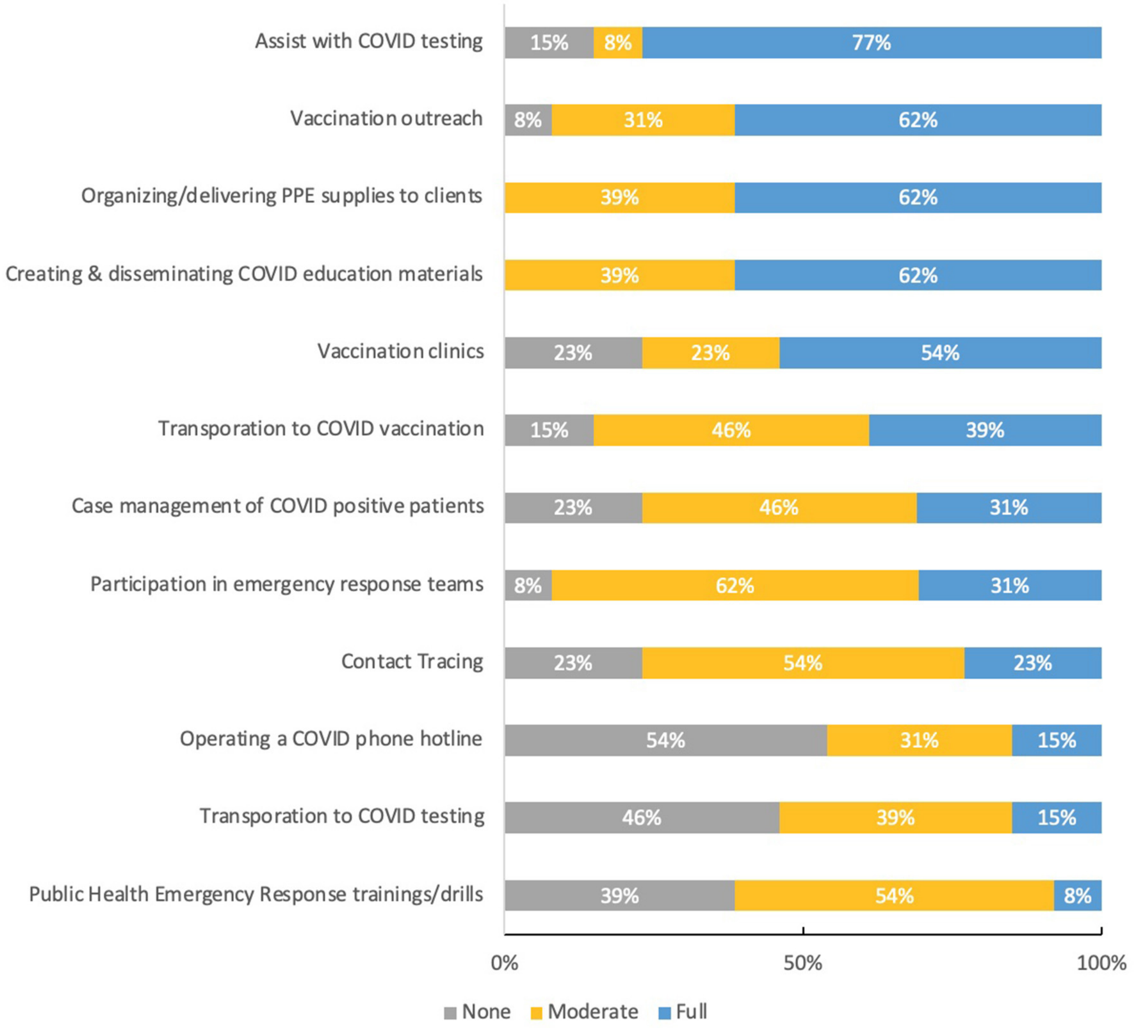

FIGURE 3
CHR manager descriptions of CHR program involvement in COVID-19 response efforts.

this information at this point in the community case study to set up the next section which explores how CHRs and programs are integrated into health care systems and teams currently.

COVID-19 demonstrated to the world how critical the CHW workforce, inclusive of CHRs, was in addressing COVID-19 inequities disproportionately experienced by Black, Indigenous and People of Color (BIPOC). As has been reported elsewhere, nationally, Indigenous and AIAN populations experienced higher age-adjusted COVID-19 mortality rates than any other racial or ethnic group (25), as well as a 1.6× higher risk of infection and 3.5× risk for hospitalization than non-Hispanic Whites (26). The COVID-19 incidence rate per 100,000 continues to be significantly higher among Indigenous AI/AN (70.01) compared to non-Hispanic Whites (24.97) (27). Indigenous and AIAN populations in Arizona have experienced a disproportionate impact from COVID-19. As May 2021 ∼25% of *all* AIAN deaths in the U.S. having occurred in Arizona (1,596 out of 6,382) (28). AIAN deaths represented between 8 and 10% of all COVID-19 deaths in the state, in spite of AIAN populations being 5% of the total population (28, 29). Although this rate has fluctuated over the course of the pandemic; in May 2020 American Indian people comprised over 12% of cases and 16% of deaths in Arizona (30). These health disparities, in concert with historical and contemporary inequities rooted in lack of access to healthcare and running water, and crowded housing, have placed Indigenous and AIAN populations at greater risk for infection and severe outcomes of COVID-19 (26, 30, 31).

Given a list of COVID-19 response categories, identified through our previous workforce assessment, CHR Program Managers were asked to rate the degree to which their program has been involved in each effort—options were presented on a three-point scale of not involved, moderately involved (occasionally), and highly involved (daily/weekly).

According to our assessment, more than three-quarters of all CHR Managers described their program as highly involved (daily/weekly) in assisting with COVID-19 testing, while slightly less than two-thirds of programs were highly involved (daily/weekly) in vaccination outreach and creating and disseminating COVID-19 educational materials. Half of all programs were also highly involved (daily/weekly) in supporting vaccine clinics. Approximately 62% of CHR Programs were described as moderately involved (occasionally) involved in their Tribes' emergency response team and or participating in emergency response training and skills. In the following section, CHR Managers describe in detail the various activities they contributed to and in some cases led.

In qualitative interviews, manager experiences of their programs' integration into COVID response efforts fell into two major categories: CHR involvement ranges from minimal (e.g., involvement limited to distributing home testing kits) to essential (e.g., invited to lead incident Emergency Operation Center or lead testing and vaccine distribution).

3.6.1. Minimal involvement in COVID response

The involvement of several CHR Programs in community COVID response was limited to distribution of home test kits and personal protective equipment (PPE). The first CHR Program manager explained that while their staff was trained to provide contact tracing, they were not invited to participate in contact tracing or incident command. CHR involvement was limited to providing home test kits and PPE (sourced through the National Supply Center) to residents during community testing events and through regular office services, and helping public health nurses identify unhoused residents for vaccination. Similarly, the main role that the second CHR Program played in COVID response was to distribute home test kits and deliver medicine to homebound clients. CHRs received contact tracing training and were initially invited to do some contact tracing and case management of positive clients but were eventually not included in this aspect of the response. Managers attributed some of their underutilization in response efforts to a lack of understanding from IHS of CHR roles and responsibilities. The third CHR Program's primary role in COVID response was to distribute COVID-related informational materials, home test kits and PPE kits to residents. IHS Public Health Nursing (PHN) and Tribal Emergency Management were responsible for testing and vaccination coordination, but due to staffing limitations and geographical challenges, they enlisted the support of a local federally qualified community health center (FQCHC) to provide both services on occasion. CHRs were brought in to support pop-up clinics, and to serve as a liaison between the FQCHC and IHS PHN.

3.6.2. Invited to be essential members of the COVID response and or vaccination efforts

The fourth CHR Program director described their strong integration into the COVID response effort in their community. CHRs had already completed FEMA training before the pandemic began, so they were well positioned to be part of the response team. The CHR manager was made the head of the Operations section of the Emergency Operation Center and CHRs provided IHS staff with information about families and individuals in the community that was essential in determining health status, risk level, and living situation. CHRs worked with PHN to assist with vaccination and testing efforts, assisted with mass testing events held at various locations including the local casino, housing authority, daycare centers, and behavioral health services. CHRs also provided case management to positive clients, which includes a focus on identifying and monitoring high-risk household members. CHRs were trained for high-risk care and case management work with COVID-positive clients designated as high-risk by IHS.

The directors of the fifth and sixth CHR Programs described a similarly high level of involvement in their communities' COVID response. From the beginning of the pandemic, both CHR programs were included in a Joint Incident Command team that coordinated the COVID response between the Tribe and the tribally operated 638 hospitals. The fifth CHR Program was tasked with managing the Tribe's entire vaccination program, coordinating weekly mass vaccination clinics. The sixth CHR Program worked with PHN to lead COVID testing efforts, assisting with mass testing events that serviced as many at 400–600 people in a day during the height of the pandemic, and provided testing of residents of the skilled nursing facility. CHRs at that program were also involved in contact tracing and were included as "essential" members of the PHN-led home visiting vaccination teams, providing explanation about the vaccine to community members. The director of the sixth CHR Program described the influence the pandemic had on the overall focus of the CHR program, pushing it from primarily health education and disease prevention to medication management and support for high-risk clients. CHRs were critical in checking on high-risk, homebound COVID-positive residents, providing case management, delivering medication, assisting with medication management, and assessing their needs. Through their efforts, data was also collected to establish a long-term COVID clinic (for "COVID long-haulers").

3.7. Integration in primary care systems and teams

Finally, we turn our attention to how the CHRs and managers perceive their current involvement in healthcare systems and teams. According to the workforce assessment, approximately, 60% of CHR managers and CHR respondents believe they are part of a primary care team, compared with 40% of respondents who reported no involvement or unsure (Table 2). Of those CHRs and managers who are part of a primary care team, more than 50% of all CHRs and managers described that PHNs, fellow CHRs, CHR managers, medical assistants, doctors, and pharmacists were part of the care team. Social workers, community members and patients, nutrition specialists and behavioral health counselors were included by less than half of all respondents as members of the care team. CHRs and managers were also asked which current modes of communication they utilize to communicate with members of the care team. Although respondents could choose all that apply, telephone messages and text were the primary form of communication. Approximately 67% of all respondents reported being involved in huddles or meetings with the care team. Major differences in perceived modes of communication occurred in relation to perceived access to an electronic health medical record,

TABLE 2 CHR program integration within health systems and teams.

Work as part of a primary care team	$N = 45$	$N = 13$	$N = 58$
Yes	60% (27)	61.5% (8)	60.3% (35)
No	20% (9)	23.1% (3)	20.7% (12)
Unsure	20% (9)	15.4% (2)	18.9% (11)
Members of the primary care team	$N = 36$	$N = 10$	$N = 46$
Registered Nurses/Public Health Nurses	91.7% (33)	90% (9)	91.3% (42)
CHR Mangers/Supervisors	83.3%(30)	60% (6)	78.3% (36)
Fellow CHRs	77.8% (28)	80% (8)	78.3% (36)
Medical Assistants	69.4% (25)	70% (7)	69.6% (32)
Doctors	66.7% (24)	80% (8)	69.6% (32)
Pharmacists	58.3% (21)	50% (5)	56.6% (26)
Social Workers	47.2% (17)	70% (7)	52.2% (24)
Community Members/Patients	44.4% (16)	20% (2)	39.1% (18)
Nutritionist/Dietitian	44.4% (16)	40% (4)	43.5% (20)
Behavioral Health Counselors	27.8% (10)	30% (3)	28.3% (13)
Current modes of communication with primary care team	$N = 42$	$N = 11$	$N = 53$
Telephone message and text	88.1% (37)	72.7% (8)	84.9% (45)
Grand rounds, huddles, meetings	66.7% (28)	63.6% (7)	66.0% (35)
Handwritten notes	64.3% (27)	63.6% (7)	64.2% (34)
Resource patient management systems	64.3% (27)	36.4% (4)	58.5% (31)
Electronic health record (EHR)	61.9% (26)	36.4% (4)	56.6% (30)
Medical chart	61.9% (26)	45.5% (5)	58.5% (31)
No formal way, in passing only	35.7% (15)	9.1% (1)	30.2% (16)
No way of communication	23.8% (10)	9.1% (1)	20.8% (11)
Perceptions of integration	$N = 45$	$N = 13$	$N = 58$
I feel I am a valid member of the primary care team			
Strongly agree	24.4% (11)	15.4% (2)	22.4% (13)
Agree	55.6% (25)	61.5% (8)	56.9% (33)
Disagree	15.6% (7)	15.4% (2)	15.5% (9)
Strongly disagree	4.4% (2)	7.7% (1)	5.2% (3)
I feel I am well integrated into the primary care team			
Strongly agree	13.3% (6)	15.4% (2)	13.8% (8)
Agree	57.8% (26)	46.2% (6)	55.2% (32)
Disagree	26.7% (12)	23.1% (3)	25.9% (15)
Strongly disagree	2.2% (1)	15.4% (2)	5.2% (3)
I feel the healthcare providers I interact with have a good understanding of my roles and abilities			
Strongly agree	26.7% (12)	15.4% (2)	24.1% (14)
Agree	57.8% (26)	61.5% (8)	58.6% (34)
Disagree	15.6% (7)	15.4% (2)	15.5% (9)
Strongly disagree	0 (0)	7.7% (1)	1.7% (1)

with 62% of CHRs believing they used an EHR to communicate with the team compared to only 36% of managers. Notably, approximately one-quarter and one-third of CHRs reported no formal way to communicate, in passing only or no way to communicate at all, respectively.

How CHRs and managers feel as members of the primary care team was also explored. This question was asked of all respondents, not only those who identified as members of a primary care team. A four-point Likert scale (*strongly agree, agree, disagree*, and *strongly disagree*) was used to assess three questions. Generally, one-quarter of respondents *strongly agreed* that they feel they are a valid member of the healthcare team and that healthcare providers they interact with have a good understanding of their roles and abilities. These trends tracked for those respondents who *agreed* (as opposed to *strongly agreed*) with these statements, with more than 50% of respondents stating they *agreed*. When asked if CHRs and managers feel they are well integrated into the primary care team, the level of *strongly agreed* responses dropped to 13 and 15% for CHRs and managers, respectively. Also notable, is the significant difference between CHRs and managers who *agreed* with this statement, 57 and 46%, respectively. Overall, although results trend positively, they also demonstrate opportunities to improve the level of integration among CHRs and managers within systems and teams.

4. Discussion

The CHRs WITH uS! workforce assessment is a set of powerful tools to generate workforce informed systems-level approaches to monitor progress toward a variety of workforce identified goals and aims related to public health and health care systems and care team integration, including COVID-19 related response systems and teams.

In pursuit of the realization of the full CHR scope of practice and enabling CHRs and all team members to practice at the top of their scope, McCarville et al. (32) identified several health systems factors associated with the quality of integration of CHWs into systems and teams. According to this model, at the health systems level, our workforce assessment identified several of these factors. We found evidence of moderate to high levels of the following factors: respondent reported working as part of a care team; mechanisms exist for CHRs and care teams to communicate; CHRs work in close physical proximity to care team members (share physical workspaces). We also identified moderate to low levels of the following factors that contribute to quality integration: CHRs having access to EMR or other medical record systems; and having a known champion or leader within the team that supports CHR integration. We found low to no evidence of the following factors: healthcare providers receive training or mentorship in working with CHRs; and protocols and procedures involve CHRs in health services delivery. What is currently unknown and yet to be explored are the final health system factors of: protocols that guide CHR participation in regular meetings with care team; and a flattened hierarchy enabling CHRs to engage in aspects of care.

4.1. Workforce policy recommendations

Over the course of the CHRs WITH uS! project, and through the efforts of the broader Arizona CHR Workforce Movement (coalition), CHR Programs have decided to engage in a Program-to-Program Mentorship (PPM) program. PPM will pair or match CHR programs that have self-identified to have demonstrated strengths, protocols, or policies in integration within systems, care coordination and closed loop referral systems development, or have experienced high level engagement within COVID-19 response efforts, with CHR programs without such experience but with the desire to engage. PPM intends to build from local knowledge, lessons learned and processes operating within CHR Programs and their related IHS and tribal systems of care. We believe such a model may increase the likelihood of adoption of systems and team integration by creating space for broader systems-level leadership and team members to engage directly through trusted channels. This direct engagement is opposed to seeking a model from outside or from a context without the level of trusted relationships or proximity required to implement new strategies over time.

CHRs WITH uS! partners and broader consortium members are currently focused on formalizing relationships with tribal programs and health systems that include: (1) establishment of formal referral process and procedures to improve communication between CHRs and IHS, (2) access to electronic health records for CHRs, (3) participation in discharge planning for clients returning to communities, and (4) formal case management policies and procedures. Partners have identified several mechanisms to integrate CHRs into systems and to fully utilize their scope of practice to benefit and address the social determinants of health and resilience with their clients.

4.2. Conceptual or methodological constraints

This community case study is not considered research by Northern Arizona University Institutional Review Board. It is not intended to be generalizable to the broader CHR workforce and is unique to the tribal CHR Programs and Urban Indian Health Centers employing CHRs within the boundaries of the state of Arizona. Despite the non-generalizability, assessment methods were conducted in highly participatory ways with workforce and management involved at each phase of the assessment including conceptualization, instrumentation, interpretation of results and dissemination of results.

Data availability statement

The datasets presented in this article are not readily available due to Tribal Data Governance. Requests to access the datasets should be directed to samantha.sabo@nau.edu.

Author contributions

SS and LO'M lead the writing of the community case study. KR provided detail review and supported the development of public health policy recommendation. BB, JH, JN, FF, MB, RM, and JY participated in the development of the workforce assessment protocol and including its focus and conversation guides. All authors contributed to the interpretation of workforce assessment results and provided detailed review of draft reports and reviewed the final versions of the community case study. All authors co-conceptualized the community case study based on the original community health representative workforce assessment results and reports. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

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EDITED BY
Durrell J. Fox,
JSI Research and Training Institute,
United States

REVIEWED BY
Svea Closser,
Bloomberg School of Public Health, Johns Hopkins University, United States
Lily K. Lee,
Loma Linda University, United States
Charles Kamen,
University of Rochester, United States

*CORRESPONDENCE
Vanessa Kitzie
✉ kitzie@mailbox.sc.edu

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Co-creation of a training for community health workers to enhance skills in serving LGBTQIA+ communities

Vanessa Kitzie[1]*, Julie Smithwick[2], Carmen Blanco[2], M. Greg Green[2] and Sarah Covington-Kolb[2]

[1]School of Information Science, University of South Carolina, Columbia, SC, United States, [2]Center for Community Health Alignment, University of South Carolina Arnold School of Public Health, Columbia, SC, United States

This paper describes creating and implementing a 30-h LGBTQIA+ specialty training for community health workers (CHWs). The training was co-developed by CHW training facilitators (themselves CHWs), researchers with expertise in LGBTQIA+ populations and health information, and a cohort of 11 LGBTQIA+ CHWs who theater tested and piloted the course. The research and training team collected cohort feedback through focus groups and an evaluative survey. Findings stress the importance of a curriculum designed to elicit lived experiences and informed by a pedagogical framework centered on achieving LGBTQIA+ visibilities. This training is a vital tool for CHWs to foster cultural humility for LGBTQIA+ populations and identify opportunities to support their health promotion, especially considering their limited and sometimes absent access to affirming and preventative healthcare. Future directions include revising the training content based on cohort feedback and adapting it to other contexts, such as cultural humility training for medical and nursing professionals and staff.

KEYWORDS

LGBTQ, LGBTQIA+, community health workers, CHW training protocol, curriculum development

1. Introduction

LGBTQIA+ populations experience significant health and healthcare disparities compared to their heterosexual, cisgender (i.e., people whose gender identities align with their sex assigned at birth) peers (1–3). These disparities arise in part because LGBTQIA+ people lack access to health-protective resources, including financial resources, affirming healthcare (i.e., healthcare that supports people's sexualities and gender identities), and social safety (4–7). Considering these disparities, LGBTQIA+ populations exhibit resilience when promoting individual and community health. Examples of resilient practices are developing positive coping strategies, resisting stigma and discrimination, and producing and exchanging new forms of affirming health information (8–10). One promising avenue to support these practices is training LGBTQIA+ leaders as community health workers (CHWs).

A CHW is a "frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery" (11). In their study of the health information practices of LGBTQIA+ people and communities in South Carolina (SC), Kitzie et al. (9) identified community leaders who informally served in CHW roles. Informed by these findings, the research team, in partnership with the Center for Community Health Alignment (CCHA) at the Arnold School of Public Health, recruited 11 SC LGBTQIA+ community leaders and trained them to become CHWs. As part of this training, the team partnered CHWs with academic librarians to co-create informational resources for the CHWs' communities. This paper reports on one project element: co-developing an LGBTQIA+ specialty training to build on CHW training and skills.

To the best of the authors' knowledge, this specialty training represents one of the first in the US to center LGBTQIA+ populations explicitly. It is intended for all CHW audiences (LGBTQIA+ and non-LGBTQIA+) and will develop and grow their cultural humility for LGBTQIA+ people and ability to identify opportunities for supporting their health promotion. This paper will outline how the team developed the training, lessons learned from cohort feedback, and future directions. Evidence-based implications can inform the development of similar trainings.

2. Background and rationale for the educational activity innovation

2.1. Background

2.1.1. CHWs and core competency training

CHWs work in communities that lack access to affirming and preventative healthcare. It is critical that CHWs share lived experiences with these communities (12). CHWs help communities access resources for their health needs, deliver professional development trainings to providers to increase their cultural humility, address mistrust of healthcare institutions by serving as a trusted bridge or cultural liaison, and engage in advocacy work to improve healthcare resources for critically underserved populations (12). A growing body of research has found associations between CHWs and improved health outcomes, utilization of appropriate healthcare services, and service cost-effectiveness (13–15).

The C3 Project, a national consensus-driven process to enhance cohesion around the CHW model of care, established a set of CHW roles and competencies that have become the basis for CHW training and practice in SC and nationwide (11, 12). The SC CHW Credentialing Council approves the CHW core competency training. It requires curricula to cover the skills identified by the C3 Project, along with two additional competencies related to quality of care and health equity.

CCHA offers a 160-h CHW core competency training. The training includes 2.5 h of content that guides culturally humble care to LGBTQIA+ communities. A variety of case studies throughout the core competency training also ask learners to consider how to work with participants who have diverse gender identities and sexualities.

2.1.2. LGBTQIA+ populations

As mentioned, LGBTQIA+ populations experience health and healthcare disparities, such as the increased risk of obesity and chronic illness, higher HIV infections and STI rates, and enhanced mental distress (16–19). Disparities vary based on identities within the LGBTQIA+ umbrella and cross-cutting identities like race and class. Pervasive stigma and discrimination against LGBTQIA+ people create insufficient social safety nets, producing these disparities (5). For instance, healthcare provides an inadequate social safety net for LGBTQIA+ populations, who often perceive doctors and hospitals as unsafe due to provider lack of knowledge, negative experiences, inability to pay for care, and provider refusal to give care (20, 21). A socio-ecological framework, which addresses health prevention efforts across four levels (societal, community, relational, and individual), offers a promising approach for identifying gaps in the social safety net spanning multiple domains, including family, peers, community, and school (22, 23).

CHWs are uniquely positioned to address gaps in LGBTQIA+ persons' social safety nets due to their relationships of trust with the people they serve and their emphasis on interventions following the socio-ecological framework (24). However, CHWs may experience similar gaps in knowledge about LGBTQIA+ experiences, identities, and needs as those experienced by medical and nursing providers and staff. Studies examining medical and nursing curricula show a median of 5 h, out of a 4-year program, devoted to LGBTQIA+ curricula-specific content hours for undergraduate medical students (25, 26) and report that 80% of nurses surveyed in 2015 did not receive any LGBTQIA+ specific training (27). Only providing information about LGBTQIA+ identities, experiences, and needs is not enough. As Stroumsa et al. (28) demonstrate, transphobia poses a significant barrier to provider knowledge about trans-specific healthcare despite the presence or absence of specific training on this topic. The effectiveness of LGBTQIA+ healthcare education initiatives "may depend not only on increasing informational knowledge but also on addressing providers' biases, whether conscious or unconscious. Educational initiatives will need to take learners' backgrounds into account, directly address prejudice and enhance cultural humility" (28).

2.2. Rationale

CHWs are poised to respond to barriers faced by communities experiencing marginalization. While LGBTQIA+ populations constitute one such community, their needs might not be met fully if CHW training reflects similar medical and nursing education gaps. For many CCHA trainees, the core competency training is the first time they have had open discussions about gender identity and sexuality, the importance of affirming care, and health disparities affecting LGBTQIA+ populations. Such limited exposure can further perpetuate misinformation, stigmatizing language, and other unintentional offenses toward LGBTQIA+ people. CCHA observed that more time and information than what 2.5 h of core competency training can cover is required for CHWs to establish cultural humility centered on LGBTQIA+ health promotion.

To address this need, a team of CHW training facilitators (who are CHWs) at CCHA, researchers with expertise in LGBTQIA+ populations and health information, and a cohort of 11 LGBTQIA+ CHWs co-developed a 30-h LGBTQIA+ specialty training. This training allows CHWs to take an in-depth look at specific disparities and inequities experienced by LGBTQIA+ populations at all four socio-ecological framework levels. The training focuses on fostering cultural humility. Cultural humility shifts from the mastery perspective adopted in cultural competency approaches to developing personal strategies for accountability in acknowledging power differentials between CHWs and clients and challenging the social and structural barriers to LGBTQIA+ health promotion (29).

3. Pedagogical frameworks

3.1. Popular education

Popular education is a form of adult education that emphasizes participation and encourages learners to reflect on their personal experiences to think critically about social issues. This type of education is "popular" because it is "of the people" and is a collaboration amongst all learners and facilitators who teach and learn from each other.

According to Wiggins (30), popular education "draws out and validates what participants already know and do, connects their personal experience to larger social realities, and then supports participants to work collectively to change their reality." Popular education places value and grounds learning on the participants' experiences and knowledge, modeling the C3 Project role of "Building Individual and Community Capacity" (12). This strategy is vital because the most important quality of a CHW, according to the C3 Project, is the "connection with the community served" (12). In literature, popular education has improved participant empowerment and health outcomes (30).

3.2. Queer pedagogy

Queer pedagogy is "a radical form of educative praxis implemented deliberately to interfere with, to intervene in, the production of 'normalcy' in schooled subjects" (31). It challenges what educators take for granted in teaching settings, such as the banking model of education, which envisions the instructor as the only person in the room possessing knowledge (32). Rather than considering knowledge as something to be mastered, queer pedagogy instead asks questions about knowledge, such as: "Who gets to know? Who gets to be considered knowledgeable? What do we refuse to know and why?" Queer pedagogy focuses less on presenting informational knowledge about LGBTQIA+ experiences, identities, and issues and instead questions why others consider these experiences, identities, and issues to be not "normal." Queer pedagogy encourages instructors and students alike to unlearn traditional assumptions they might have about LGBTQIA+ people based on what they take for granted as normal within systems like healthcare (33).

3.3. Cultural humility

Cultural humility is "a foundational concept and skill for guiding the work of CHWs" (34). Cultural humility challenges and readdresses power imbalances between the service provider and client; these imbalances have sustained discriminatory practices and contributed to inequitable access to care. Cultural humility asks learners to acknowledge the limits of their knowledge about other cultures and that cross-cultural work involves lifelong learning and self-reflection. For CHWs, this critical component of client-centered care requires openness and humility when working with individuals and defined populations. Facilitating with a culturally humble lens is imperative and fosters a safe learning environment inclusive of all diverse values, backgrounds, and identities present.

The pilot cohort and facilitators of this training represented diverse, intersectional identities (i.e., how people's identities can overlap in ways that compound the privilege/oppression they experience), including age group, ethnicity, cultural background, and LGBTQIA+ identities. Regarding critical issues discussed in this course, learners considered existing cis/heteronormative norms and how these can exacerbate health disparities within LGBTQIA+ communities. Using a culturally humble lens when working with LGBTQIA+ communities builds trust and openness. It also acknowledges that no one identity or cultural value is more meaningful or superior to others and that an individual's reality should be recognized as different from the realities of those identifying outside of cis/heteronormative norms.

4. Curricular outline and learning environment

4.1. Curricular outline

The team developed a 30-h LGBTQIA+ specialty training meant to be taken after completing the 160-h core competency training. From May–July 2021, the team began planning the curricular outline by identifying five main areas of focus, which ultimately became the course modules: (1) terminology and history of LGBTQIA+ identities (5 h); (2) intersectionality and LGBTQIA+ identities (10 h); (3) LGBTQIA+ health issues (10.5 h); (4) resources and strategies for LGBTQIA+ health promotion (2.5 h); (5) advocacy and outreach to LGBTQIA+ people and communities (2 h). The team identified these areas based on several factors, including CCHA's observations of prior CHW training participants' reception of and feedback about the 2.5 content hours focused on LGBTQIA+ topics; the team's previous research concerning health issues faced by LGBTQIA+ populations and their health information work (9, 35–37); feedback from an eight-person advisory board comprised of LGBTQIA+ community leaders, CHWs, and researchers in Public Health and Information Science fields.

The training is unique to CHWs because it focuses on the critical roles that CHWs play as information and resource intermediaries between communities experiencing marginalization and healthcare institutions (11). For instance, CHWs attending this training discuss safe housing considerations when making referrals, share pronouns when facilitating groups, and understand the need to add LGBTQIA+ affirming providers to their resources; all these activities address socio-ecological health interventions. Another reason the training is unique is that CHWs and allies developed it utilizing best practices in CHW training. Some team members who developed the training have backgrounds in Information Science, which focuses on identifying, evaluating, and disseminating health information resources; their expertise also informed the training and focused on CHW intermediary roles.

After identifying the modules, the team created specific topics and learning outcomes for each, informed by feedback from the sources above. The team also developed two sample units. The pedagogical framework informed the development of content, especially queer pedagogical approaches. Popular approaches include (1) recognizing the limits of dominant ways of knowing; (2) examining ignorance from the perspective of active resistance to learning about specific topics; (3) ensuring learning materials represent queer perspectives and experiences; (4) interrogating disclosure, specifically who must disclose what about themselves in given situations or circumstances (38). Examples of how these approaches informed content development were (1) locating LGBTQIA+ health disparities and challenges within healthcare systems and institutions—not individuals; (2) engaging in reflexive exercises meant to foster cultural humility by asking participants to identify their preexisting biases toward specific identities and issues; (3) integrating content created by LGBTQIA+ individuals with formal expertise and lived experiences into the training; (4) actively discussing labels and terminology, including using terms that actively make visible identities often not labeled or taken for granted because society considers them normal (e.g., allosexual, which refers to people who experience sexual attraction). These strategies also corresponded with popular education and cultural humility principles.

One unique element of the training's pedagogical format was the inclusion of expert videos. Before the training, the team contacted nine LGBTQIA+ people with lived experience and formal expertise in curricular subject areas and asked them to record an informational 10–15-min video presentation. An example was an academic researcher specializing in health and aging among queer, transgender, and intersex populations. The expert presented findings from their research about intersex affirmation in health care settings and reflected on these findings based on their experiences as an intersex person. The team identified experts based on their networks within the fields of Information Science and Public Health and provided each expert with $250 honoraria for their contributions.

Table 1 displays a sample unit for each module with accompanying learning objectives, definitions, and activities.

4.2. Learning environment

The specialty training was online using Zoom, required participant cameras to be always on (a requirement of the credentialing body), and emphasized participatory learning. Facilitators facilitated open discussion amongst learners, reinforcing critical concepts by utilizing their life experiences and expertise. The training used learning aids, tools, and programs to foster and maintain the integrity of the participatory learning environment. Each class integrated multiple methods, including case studies and role plays using Zoom breakout groups, collaborative notetaking using Jamboard (interactive whiteboard), and knowledge checks using the game-based learning platform Kahoot!.

The facilitators covered the 30-h curriculum over 2 weeks, meeting with training participants for three consecutive hours on weekdays. Each training session began with an icebreaker and an overview of the plan for the day. Facilitators would then cover course material consisting of Google slides and multimedia, including audio clips and videos.

Following the presentation of course content, facilitators would ask training participants to engage in collaborative discussions and activities. A break followed this engagement, and the structure would resume until the session's conclusion. Facilitators provided training participants with a link to the slides and additional resources after each session.

5. Results to date and assessment

5.1. Processes and tools

Receiving feedback on the training from CHWs and LGBTQIA+ people was vital. The team recruited a cohort of 11 LGBTQIA+ community leaders from SC to provide this feedback. The cohort provided input on the curriculum as it was being developed and again at the culmination of the training. Recruitment methods relied on the research team's pre-established network of participants and a contact list of visible LGBTQIA+ and affirming communities in the state. Those interested attended an interest meeting and completed a questionnaire developed by CCHA and informed by C3 standards. The team met to evaluate the responses, looking for individuals who exhibited essential CHW skills and competencies. It was also crucial that the cohort reflect diverse LGBTQIA+ and intersectional identities. Figure 1 displays a word cloud of labels contributed by participants to describe their sexualities and gender identities. Table 2 shows basic demographic information describing the cohort.

In July 2021, the cohort gave feedback on the training *via* a half-day virtual theater testing session of two sample units. Theater testing is a methodology where individuals demonstrate the content of a program to a relevant audience to elicit feedback and opportunities for improvement (39). Specifically, two team members acted as training facilitators and presented 2 h worth of content to the cohort as if they were engaged in the specialty track training. After the facilitators presented the sample units, the cohort provided qualitative, large-group feedback. This feedback focused on both units and the entire curriculum, including topics and subtopics covered, and learning objectives. Based on the feedback, the team revised the curriculum and materials. After concluding core competency training, the cohort took the 30-h training in December 2021. The cohort provided general quantitative feedback on both trainings using the standard, Likert-item evaluative survey given by CCHA to all training participants. In addition, the cohort provided qualitative feedback about both trainings in two focus groups, comprised of 5–6 people each, which

TABLE 1 Sample unit with learning objectives, definitions, and activities.

Module 1 sample unit: LGBTQIA+ 101
Learning objectives:
• Summarize LGBTQIA+ demographics in the United States
• Define basic LGBTQIA+ terms and concepts
• Explain how sex, sexuality, and gender are socially and medically constructed
• Employ LGBTQIA+ inclusive language
Key definitions
Gender identity; sex assigned at birth; gender expression; gender roles; sexual orientation; romantic/emotional orientation; bisexual; pansexual; asexual; transgender; cisgender; agender; genderfluid; genderqueer
Sample activity
In groups of 2–3, come up with a demographic question or questions you want to know about LGBTQIA+ people in SC. See if you can answer the question you came up with by searching online.
• What was your question?
• What, if anything, was challenging or difficult about this exercise?
• What do you think made this exercise challenging/difficult?
• What questions remain for you after this exercise?
Module 2 sample unit: Introduction to intersectionality
Learning objectives:
• Define intersectionality
• Describe how intersectionality originated (Truth, Crenshaw, Hill Collins)
• Dispel common intersectionality and myths
• Apply lens of intersectionality to LGBTQIA+ identities and issues
Key definitions
Intersectionality; matrix of domination; top-down vs. bottom-up approaches; DeGraffenreid v. General Motors
Sample activity
Pick a health topic you are passionate about. Write this topic on the Jamboard as well as your answers to the following questions:
• How do LGBTQIA+ people and communities experience your chosen topic?
• What other important identities might inform how LGBTQIA+ people experience this topic?
• Are there groups left out of the discussion?
• Are some groups overrepresented? Why might this be?
You may complete outside research to answer these questions.
Module 3 sample unit: Pursuing gender affirmation
Learning objectives:
• Define gender affirmation
• Provide examples of social, psychological, legal, and medical approaches to achieve gender affirmation
• Describe HRT and who uses HRT within LGBTQIA+ communities
• Identify barriers to accessing HRT within among LGBTQIA+ communities
• Develop advocacy strategies for HRT use within LGBTQIA+ communities
Key definitions
Gender affirmation (legal, medical, social); HRT (estrogen, testosterone, low dose); puberty blockers
Sample activity
In groups of 2–3 discuss:

(Continued)

TABLE 1 (Continued)

• Do you (or someone you know) have any experience with taking hormones? Do we notice patterns in who takes hormones of their experiences? If so, what are they?
• If you do not know someone personally, see if you can find someone's account of going through HRT. What was the process they had to go through? How long did the process take? Were there any challenges or barriers they experienced?
Module 4 sample unit: Resources for LGBTQIA+ health promotion
Learning objectives:
• Describe insurance coverage for LGBTQIA+ people in SC
• Identify local health resources and programs that offset insurance costs for LGBTQIA+ populations
Key definitions
Affordable Care Act; Medicaid; health insurance marketplace; quality of life resources
Sample activity
Your friend is taking Fenoglide for their cholesterol. They're struggling to afford their medication and ask you if know of any pharmacies that have the generic version of their medication, fenofibrate, on their formulary list.
In breakout groups, locate a pharmacy that includes fenofibrate on their formulary list. Then, discuss:
• What was this experience like?
• What challenges may people face when seeking ways to offset medication costs?
Module 5 sample unit: Advocacy and outreach to LGBTQIA+ people and communities
Learning objectives:
• Ask questions about local LGBTQIA+ organizations and communities in a safe environment
• Identify tactics used by local LGBTQIA+ communities and organizations to advocate for their members
Key definitions
Advocacy; outreach
Sample activity
Pair and Share: Recall a time when you or someone you know advocated on behalf of a person or a group of people.
• What happened?
• Who was involved?
• What was the issue or issues that inspired the act of advocacy?
• Was this act effective? Why or why not?

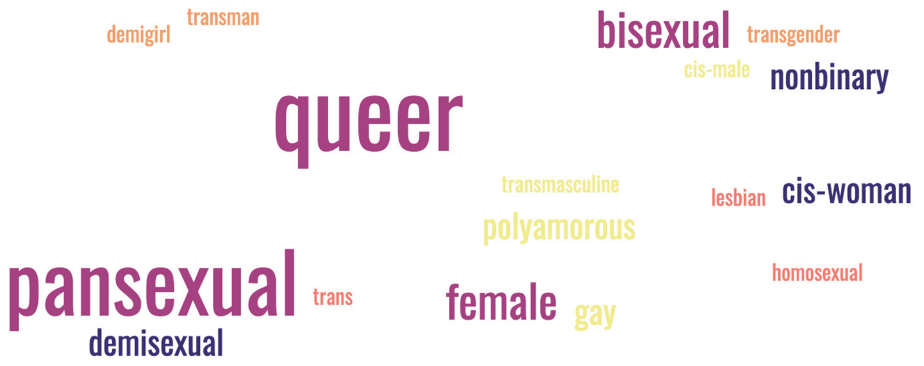

FIGURE 1
Labels used by participants to describe their sexualities and gender identities.

occurred in March-April 2022. Table 3 displays sample items from each of the feedback instruments.

This paper focuses on specific feedback from the focus groups after the training. The research team qualitatively analyzed the feedback for themes using thematic analysis (40). The team imported the verbatim focus group transcripts into NVivo, a qualitative research analysis environment. Three team members then coded 20% of the data (transcript excerpt) line-by-line using

TABLE 2 Participant demographics.

Races/ethnicities	Black	5
	White	3
	Latinx/Latine	2
	Multiracial	1
Education levels	Bachelor's degree	5
	Some college credit	5
	Associate's degree	1
	Master's degree	1

open coding (41). The team members then met to review initial codes, combining and condensing them based on this discussion. The team resolved disagreements using NVivo's coding comparison query, which identifies coding discrepancies that served as a starting point for conversation. The team then applied the initial codes they decided on to the remainder of the transcripts and met again to identify themes or larger patterns describing what participants were saying. The team then created a codebook with themes and their related codes. Each code had a definition followed by an illustrated transcript excerpt. Since constructivist grounded theory traditions informed analysis, the team deemed inter-coder reliability calculations inappropriate due to the analytic process's iterative, recursive nature (42). To protect confidentiality, the team assigned cohort members a random number.

5.2. Themes from focus groups

5.2.1. Representation of LGBTQIA+ experiences, identities, and issues in training content

The cohort noted the importance of revising the specialty training to balance content between those who might take the training with backgrounds in LGBTQIA+ identities and issues and those without these backgrounds. Participant 757 stated that parts of the training were "redundant" given the cohort's lived experiences and history of community health outreach, engagement, and support. However, the same participant cautioned that "not everything's gonna maybe sound redundant to [other cohorts]. And I have to constantly remind myself that [future cohorts] are people that never heard of this." Participant 265 stated: "If you're gonna be working with the queer community, and you're not already a really knowledgeable member, [this training] is supposed to help you do that."

While a team of many members with LGBTQIA+ identities developed and facilitated the training, not all identified as LGBTQIA+. Both focus groups expressed the perception that specific facilitators without LGBTQIA+ identities may have sometimes felt discomfort discussing LGBTQIA+ identities and issues. Participant 251 stated, "I don't think there's a level of comfort there yet," further identifying "moments of awkwardness that I think we felt, and it was like, oh, are you having a, well, this is hard for you."

5.2.2. Application of training to CHW practice and provider education

The training informed cohort members' practices as CHWs. Participant 251 reported that the training made him more proactively and intentionally think about opportunities to engage in client-centered advocacy: "I've actually been listening more in various places that I go. So even my own doctor's appointments, um, things like that, like I'm listening more and paying attention to things that would make folks uncomfortable." Participant 757 addressed how the training informed her professional practice and the importance of health worker education by describing plans for delivering the training to Spanish-speaking CHWs: "I'm gonna co-facilitate [the training] for people at [organization] and do it in Spanish. That would be very helpful, very helpful because it has a bunch of stuff that are everyday questions from my coworkers."

Participant 757 highlighted provider education as a form of advocacy, stating that the purpose of "creating and troubleshooting" the training is to "teach others how to, I think providers, I think, I mean, this should be something across the board, especially here." The participant noted that the specialization must be adapted for medical, nursing, and professional development contexts. Since the full training might be "too long, or because it's too many hours," the participant suggested compiling essential training content into "a cheat sheet where you can like actually bring somebody for like an hour [who] can do like a lunch and learn." The participant noted that the training should be extended to all staff interacting with LGBTQIA+ clients: "This needs to be offered to not only a healthcare provider but the reception upfront."

5.2.3. Accommodating different learning styles and learners in training delivery

This theme and the following address feedback on the core competency and specialty training. The cohort identified several elements of the learning environment and structure that could be improved. Participant 251 suggested considering additional learning styles when designing and organizing training content: "I'm a visual learner. And so, like even having a color coding, you know, that I've got, okay, these things need to go for here." Participant 265 noted that supplemental learning materials, such as "websites, videos, questionnaires" for each topic, would "allow us to get deeper into the topic we're working with." Participant 251 expressed "stress" and "anxiety" that emerged due to training demands.

Participants also shared feedback specific to each training. Participant 251 suggested creating a "study guide for the specialty training." Participants expressed negative affective feelings about the core competency training centered on the CHW certification exam. Participant 265 stated that the cohort was "freaking out" about the exam, while Participant 35 described the exam as "nerve-wracking."

5.2.4. Accessing formal and experiential authority and expertise

Participants identified the participatory learning elements of both trainings as valuable in strengthening their connections to

TABLE 3 Feedback instrument sample items.

Feedback instrument	Sample items
Theater testing focus group	• How well did today's presentation describe the health issues, questions, and concerns experienced by you and your communities? How about the curriculum?
	• If you could change one thing about today's presentation, what would it be? How about the curriculum?
CCHA evaluation survey	• I am confident in my ability to use culturally appropriate communication skills when serving the community (Likert scale)
	• I am able to accurately describe the community and population I serve. This includes an understanding of their major health issues, social determinants of health, and disparities (Likert scale)
Post training focus groups	• If you had a friend or colleague interested in attending this training, what would you tell them?
	• Having completed this training, what other areas or topics would you like additional guidance and support on?

others with experiential authority and expertise. Participant 35 said that before the training, they felt like the "lone" LGBTQIA+ CHW in their specific region. By engaging with other cohort members during participatory learning activities, the participant discovered their cohort mates were "doing and thinking and asking the questions, just like I'm doing and thinking and asking the questions," which facilitated "getting to build bigger partnerships" and "access to [interpersonal] resources."

The cohort also identified the certification process as critical to advancing their legitimacy as CHWs. Participant 251 explained: "We live in a society where having that certification leads credibility to what we do," despite the fact "that we already do a whole lot of these things … having that official certification, someone is like more likely to listen." One crucial implication of certification was the potential to connect with new job opportunities. Participant 757 described cohort members expressing a desire to "work with [CHW organizations]" and asking, "do they need community health workers? I'm certified now."

6. Discussion

6.1. Lessons learned

Cohort feedback and facilitator experiences denote several lessons. One relates to the need in the CHW field for this type of training. As cohort members shared, the training is particularly relevant for non-LGBTQIA+ CHWs with limited experience in LGBTQIA+ identities and issues. While some content may have been repetitive for the cohort, they said that the training increased their capacity for community-based advocacy, suggesting the training's relevance for CHWs who belong to LGBTQIA+ communities.

Content from the training is also extensible to other healthcare contexts like medicine and nursing. Of course, facilitators may need to adapt the methodology and instructor choice to their pedagogical style, such as a CHW and nurse co-facilitating training for nurses. Based on prior research surveying medical provider knowledge of LGBTQIA+ experiences, identities, and needs, training content would need to focus on increasing informational knowledge and addressing provider biases. For this reason, modules covering the terminology and history of LGBTQIA+ identities, resources and strategies for LGBTQIA+ health promotion, and advocacy and outreach to LGBTQIA+ people and communities would be particularly relevant. Additionally, content from the LGBTQIA+ health issues module should be integrated into the training, primarily centered on issues that practitioners have less knowledge about, such as gender-affirming care (43).

Feedback affirmed the importance of CHWs and members of LGBTQIA+ communities co-creating and facilitating course content. This strategy ensures that facilitators have enough knowledge about LGBTQIA+ identities and issues to exercise flexibility during facilitation based on the lived experiences and prior knowledge of training participants. Some groups may be new to these topics and require basic entries. Others, like the cohort, may be intimately familiar with these topics and appreciate a deep dive into underrepresented ones like polyamory and kink. A related issue entails addressing the biases or even outright discrimination that certain CHWs taking the training may have toward LGBTQIA+ identities and certain identity intersections (e.g., a queer Black man). While queer pedagogical principles informing the course content give training participants multiple opportunities to identify and challenge their biases, there may be other situations where participants are recalcitrant to incorporating new ways of knowing into their practice. In these instances, there must be careful consideration made by the training team of how to moderate participation in training. One potential avenue may be a brief questionnaire that prospective training participants complete before the training that attempts to gauge their receptivity to unlearning homo- and transphobia. Another idea would be an exercise around positionality during which all training members analyze and share their lenses, thereby helping the cohort start from a place of understanding that their experiences and perspectives will present strengths and challenges to their experiences during the course.

Additional insights suggest reinforcing that cultural humility is a lifelong process during training. Facilitators and participants have much to learn from each other. Engagement guidelines like the "oops and ouch" method are informative here. Facilitators encourage individuals to say "ouch" when someone says something that hurts. In return, the person who said the hurtful thing is encouraged to say "oops" and apologize for how their intentions did not match their impact. The person then would be encouraged to do additional research to understand why this mismatch occurred. With this ground rule established for constructive and respectful dialogue, learners can become aware of their biases, microaggressions, and prejudices. As a facilitator, encouraging and participating in this practice can increase participant trust, which might make them more willing to openly address perceptions of facilitator discomfort in discussing certain LGBTQIA+ topics.

A final lesson relates to both trainings, as cohort members identified the need to enhance their adult learning elements. As evidenced in Section 5.2.3, cohort members expressed stress and anxiety with aspects of the training. Such expression of negative affect likely represents the cohort's background as adult learners who have not necessarily been in educational settings or taken an exam for a long time. During the training, the team designated a contact from CCHA who was not involved in the trainings to be available to the cohort for them to express concerns. That contact would then communicate these concerns back to the team. In actuality, the cohort tended to communicate with the research team members about their concerns, who then shared them with the training team. The training team addressed the concerns reactively, such as by creating a study guide for the certification exam. Future iterations of the training can proactively consider these adult learning concerns by engaging in strategies like creating an online learning platform with scaffolding for course requirements and CHW credentialing procedures and providing secondary course materials. If available, an instructional designer may consult on this platform's development. Facilitators can also integrate scaffolding into the beginning of each lesson by quickly reviewing the course content, how to access it, and how learners can use it. Finally, all training materials should be reviewed for accessibility, such as through a program like Quality Matters (https://www.qualitymatters.org).

6.2. Practical implications

Implications from the specialty training's design, testing, and feedback related to how it can be improved and iterated for different audiences and contexts. The training team is incorporating cohort feedback into the curriculum to offer a revised version to CHWs throughout the state and beyond. These changes will be iterative and continue as the training is taught since information and terminologies are constantly changing. The team is also integrating cohort members' lived experiences as case studies during facilitation.

Further, the team is open to exploring adapting the training to different contexts, both within and outside CHW professional development. An example of a potential adaptation is to shorten the training into a half-day workshop for CHWs, medical and nursing professionals, and staff. This adaptation would also address healthcare workers' noted lack of education and professional development on LGBTQIA+ experiences, identities, and issues (27). Connecting nursing and medical professionals and staff to CHWs facilitating this training opens new avenues for potential partnerships.

6.3. Role of CHW cohort in co-creation

A final point of discussion reflects on the role of the 11 LGBTQIA+ CHWs in co-creating the curriculum. The team noticed that this feedback became more detailed over time as the cohort became more familiar and comfortable working with the team across the 2-year Project. It also presumably helped that many team members identified as LGBTQIA+, which established a shared experiential understanding of this population's larger health challenges. Two cohort members joined the CCHA training team working on specialty training revisions. This situation has ensured that revisions attend to cohort feedback since they are made by individuals who still communicate with the other cohort members. Further, these members might be more comfortable disclosing specific feedback to their cohort members.

These observations suggest that others who may wish to engage in similar work should adopt strategies for engendering long-term, sustainable relationships with the communities for whom the training is directed. Not doing the work and giving resources toward establishing these relationships can potentially lead to more surface-level feedback not reflective of what the community wants.

7. Limitations

Project limitations related to the learning environment and feedback received. The learning environment was shaped by SC CHW Credentialing Council rules that required all participants always to keep their cameras on. However, this requirement could constitute an invasion of privacy if participants are in private spaces where they do not wish for a camera to intrude. In some cases, having the camera on was a safety concern, as participants would stream parts of the training from their phones while driving. While the facilitators encouraged these participants to refrain from this activity, the credentialing requirements may have pressured participants to do so to receive training credit.

Video streaming requires stable, consistent access to technology, which was not a condition shared by all participants. It was common for participants with unstable access to be kicked out of the Zoom platform, causing them frustration. Ableist assumptions pervaded the learning environment, such as a fast delivery pace and lack of readily available accommodations for different learning styles (e.g., lack of closed captioning in some videos).

Due to scheduling difficulties, two cohort members did not participate in the focus groups following the training. While cohort feedback is invaluable and reflects a rich diversity of identities and experiences, cohort members are not community spokespeople. Therefore, facilitators must continue iterating and testing the specialty training with new cohorts.

A final constraint is balancing the need for specialty training and its magnitude with time constraints. While cohort feedback was predominately additive, subsequent revisions must balance these additions within a 30-h constraint. A way to address this concern is by facilitators creating broad learning objectives for the full training (rather than objectives at each level, which is how the training is currently designed) and tailoring content to address these objectives.

8. Conclusion

The development of a specialized training course for CHWs about how to reach, better understand, and serve members of the LGBTQIA+ population in culturally appropriate and humble ways helps fill a gap in the CHW field and is a critical step in advancing CHWs' ability to work with diverse individuals in their communities. Incorporating this training into CHW education and skill development processes can enhance access to healthcare and other health and social resources that LGBTQIA+ individuals may benefit from. The methods used to develop the curriculum are notable, as it was co-created by CHWs, community-engaged researchers, and leaders within LGBTQIA+ populations, illustrating a best practice in the CHW and community engagement fields. The intentionality around incorporating popular education, queer pedagogy, and cultural humility was both purposeful and essential. In the future, the training and curriculum development teams will continue to incorporate feedback and lessons learned from the initial cohort and research process to revise and shape a training program that can benefit CHWs and other professionals and enhance services for LGBTQIA+ communities.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by University of South Carolina Institutional Review Board. The patients/participants provided their written informed consent to participate in this study. Written informed consent was not obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article. No potentially identifiable human images or data are presented in the manuscript.

Author contributions

The authors confirm contribution to the paper as follows: Project conceptualization and design: VK and JS. Development of training materials and facilitation of training: VK, CB, MG, and SC-K. Data collection: VK and MG. Analysis and interpretation of results: VK. Draft manuscript preparation: VK, JS, CB, MG, and SC-K. All authors reviewed the results and approved the final version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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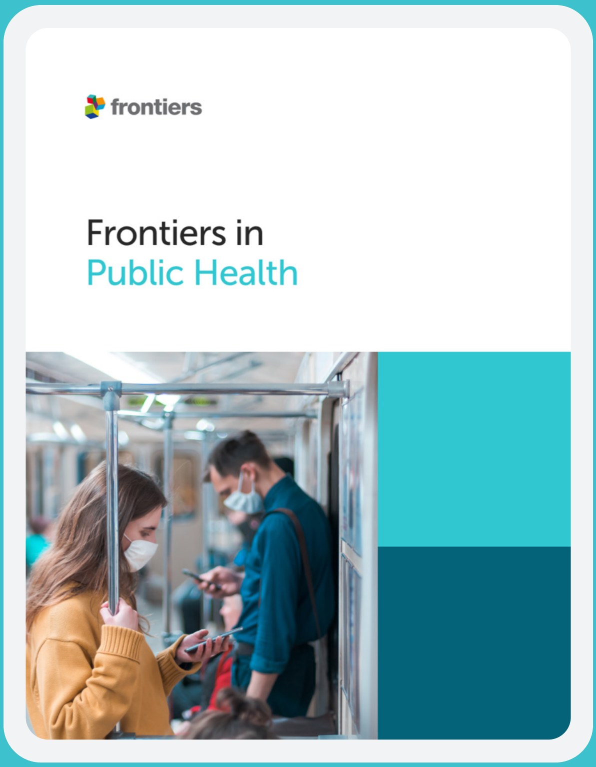
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