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Lay health worker research personnel for home-based data collection in clinical and translational research: Qualitative and quantitative findings from two trials in hard-to-reach populations

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Abstract

Aims: The role of lay health workers in data collection for clinical and translational research studies is not well described. We explored lay health workers as data collectors in clinical and translational research studies. We also present several methods for examining their work, i.e., qualitative interviews, fidelity checklists, and rates of unusable/missing data. *Methods:* We conducted 2 randomized, controlled trials that employed lay health research personnel (LHR) who were employed by community-based organizations. In one study, $n = 3$ Latina LHRs worked with $n = 107$ Latino diabetic participants. In another study, $n = 6$ LHR worked with $n = 188$ Cambodian American refugees with depression. We investigated proficiency in biological, behavioral, and psychosocial home-based data collection conducted by LHR. We also conducted in-depth interviews with lay LHR to explore their experience in this research role. Finally, we described the training, supervision, and collaboration for LHR to be successful in their research role. *Results:* Independent observers reported a very high degree of fidelity to technical data collection protocols (>95%) and low rates of missing/unusable data (1.5%–11%). Qualitative results show that trust, training, communication, and supervision are key and that LHR report feeling empowered by their role. LHR training included various content areas over several weeks with special attention to LHR and participant safety. Training and supervision from both the academic researchers and the staff at the community-based organizations were necessary and had to be well-coordinated. *Conclusions:* Carefully selected, trained, and supervised LHRs can collect sophisticated data for community-based clinical and translational research.

Introduction

Community-based data collection allows translational researchers to observe participant behaviors in their own environment and under real-world circumstances, reducing threats to contextual validity [1]. However, logistics of collecting such data are challenging. This is particularly true when the sample is low-literacy, low-numeracy, non-English speaking, and living in low-income conditions.

Accurate, complete, and culturally sensitive data collection practices are important for rigorous study of hard-to-reach populations. Lay health workers (LHWs; a broad term we mean to encompass, for example, community health workers (CHWs), *consejeras, promotoras*) are known to be successful in recruiting participants to clinical and translational research studies [2]. Yet, even as their role expands [3] to include research [4] LHW research training, supervision, and data collection skills are not well described and little is known about LHW perspectives about their role in research [5].

The data that do exist suggest that LHWs may have the potential to successfully contribute to data collection for research studies. For example, one study compared LHWs to health professionals in calculating an absolute cardiovascular disease risk score with a simple, non-invasive screening indicator [6]. Of 42 LHW trainees in 4 LMICs, 42 were deemed qualified to do fieldwork. Across 4049 screenings, the mean level of agreement between these CHWs and health professionals was 96.8%. However, in a different study, $n = 348$ government-employed LHWs in Brazil completed a 20-item, multiple-choice quiz measuring reading, comprehension, and problem-solving for epidemiological research on people with disabilities [7]. Participants

answered only 65% of questions correctly, but the training for these LHWs was not described. Another study from the same group compared data collected by LHWs who had received 10 hours of training to data collected by researchers [8]. It showed good level of agreement across 28 variables, but LHWs substantially underestimated the rate of disability. The authors suggest that moderating factors, specifically the level of burden of their clinical workflow, may effect LHW performance in research projects.

Thus, there is a need to understand LHW roles, skills, training, and supervision related to research activities [9]. We have become increasingly interested in developing the research skills of LHWs. We call LHWs trained in these methods lay health worker research personnel (LHR). Most academic research centers do not employ LHR, necessitating partnerships between the researcher and a community-based organization (CBO). The nature of these partnerships may also effect LHR performance and satisfaction.

The purpose of this paper is to describe two randomized trials involving researchers based in academia and LHR based at CBOs. For each study, we employed different methods to explore LHR in their research roles. The first study was called Community Health Workers Assisting Latinos Manage Stress and Diabetes (CALMS-D), a randomized trial of a group stress management intervention for Latinos with type 2 diabetes. For the LHRs working in CALMS-D, we (1) describe LHR training and supervision, (2) present independent observer reports of LHR fidelity to protocols, and, (3) report LHR perspectives on their roles as provided in qualitative, in-depth interviews. The second study, Diabetes Risk Reduction through Eat, Walk, Sleep, and Medication Management (DREAM), was a randomized trial that compared interventions to reduce diabetes risk among Cambodian American refugees with depression. For the LHRs working in the DREAM study we (1) describe LHR training and supervision, and, (2) report rates of missing data for behavioral measures and sensitive psychosocial self-reports along with supervisor subjective impressions of LHR cultural consonance. We conclude with a discussion of the unique value LHR bring to clinical and translational research and challenges to be considered in this work.

Study #1 Methods – CALMS-D

For CALMS-D (NCT01578096), two universities (Yale School of Public Health and UConn Health) were the lead organizations providing scientific direction, fiscal oversight, and reporting to the sponsor (NIH; Table 1). Recruitment occurred through an urban outpatient clinic associated with Hartford Hospital. LHR were employees of a non-profit CBO, the Hispanic Health Council. The position posting can be seen in the Supplemental Material #1. Two LHR were existing employees, and one was hired specifically for this study as an interventionist (who only conducted in-session data collection). The study coordinator was a bilingual, bicultural post-doctoral fellow who was employed by UConn Health and assisted in virtually all aspects of the study.

All CALMS-D procedures were approved by the UConn Health Institutional Review Board (IRB; #15-164-S) and there was an IRB reliance agreement between the IRBs of UConn Health, Yale University, Hartford Hospital, and the Hispanic Health Council. One of the Principal Investigators (RPE) had collaborated with the Hispanic Health Council and Hartford Hospital for decades, an important relationship for effective community-engaged research.

CALMS-D was a two-armed randomized trial among Latinos with type 2 diabetes comparing diabetes education vs diabetes education plus 8 sessions of group stress management psychoeducation [10]. A sub-study [11] of the parent trial used a 7-day micro-longitudinal design to observe the temporal unfolding of distress, diabetes self-care behaviors, glucose, and autonomic function. Another sub-study [12] used experimental physiological tasks (sit-to-stand, handgrip) to observe autonomic nervous system reactivity.

LHR Training

See Table 2 for LHR training details. Due to the relatively low educational attainment of LHR, their training followed guidelines of clear communications for teaching low-literacy learners [13,14]. For active skills, our principles included break up complex tasks into smaller steps; make sessions interactive and activity-based; encourage hands-on practice for supplies and equipment; use multimodal learning (written text, pictures, videos, slide shows, live practice); encourage questions; work in teams; take breaks; provide time for live practice in-session and in-between sessions; allow plenty of time to avoid a sense of time pressure; provide booster sessions; create a supportive, non-judgmental atmosphere where it is "safe to make mistakes"; and, positively reinforce participation in learning.

For written training materials, principles included use text written at or below a 6th-grade level; use bulleted lists; use short sentences that are written in the active voice; chunk materials; give context before detailed information; use sized 10–14 font; keep the right margin jagged and not justified; place illustrations next to the related ideas in the text; use visuals (flow charts, diagrams) rather than paragraphs for complex ideas; use icons to summarize and communicate complex ideas quickly and easily; and, read aloud when possible.

In addition to the details in Table 2, we also spent time delineating specific roles, responsibilities, and expectations of the LHR as recommended [15]. For example, only one LHR, who was primarily an interventionist, collected data regarding perceived stress levels before and after intervention sessions. To help minimize confusion and avoid potential conflict, we also clarified the role and expectations for the LHR for other team members.

CALMS-D LHR were trained in research methods, human subjects protection, and data collection protocols. See Table 2 for details of training. LHR training was spread across several weeks with homework and practice between training sessions. Training included a manual loosely based on the interviewer training manual for the Behavioral Risk Factor Surveillance System [16] and the Puerto Rican Elderly Health Conditions project at the University of Puerto Rico [17]. (The CALMS-D manual can be requested from the author or found at https://health.uconn.edu/diabetes-research/community-based-research/). Training materials also included several online tutorials and interactive training sessions by the investigators. LHR were given checklists to follow for each measure, and, when participants needed to comply with instructions to complete the measure, LHR were given a simplified participant handout to review and leave with participants. The bilingual study coordinator (ABM) was centrally involved in all trainings. LHR also participated in role-play of data collection, including how to handle challenging cases.

Supervision

The lead investigator based at the community-based organization (SSP) oversaw the fieldwork and provided supportive supervision to LHR throughout the study. As recommended [15], supervision

Table 1. Overview of CALMS-D and DREAM studies

	CALMS-D RCT	CALMS-D sub-study 1	CASMS-D sub-study 2	DREAM
Study design and primary outcome	2-arm RCT: diabetes education vs diabetes education + stress management. Outcome: HbA1c and depressive symptoms	7-day micro-longitudinal observation of relationships between stressors, mood, health behaviors, and glucose	Single session of observation of autonomic responses to physical challenges	3-arm RCT: social services vs lifestyle vs lifestyle + pharmacist. Outcome: HbA1c, depressive symptoms, insulin resistance
Methods for evaluating LHR	Independent observer fidelity checklists	Independent observer fidelity checklists	Independent observer fidelity checklists	Rates of missing/unusable data
	In-depth interviews	In-depth interviews	In-depth interviews	
# CBOs employing LHR	1	1	1	2
Participants	*N* = 121 low-income, Latino, urban, type 2 diabetes, reside in Hartford, CT. Spanish speaking	*N* = 50 from parent study	*N* = 35 from parent study	*N* = 188 low-income, low-literacy, Cambodian, elevated depressive symptoms, high risk for diabetes, reside in CT, MA, or RI. Khmer speaking
LHR	3 Latina. Bilingual Spanish/ English speaking and reading. Educational attainment high school graduate to some college courses	Same as for parent study	Same as for parent study	8 Cambodian, born in Cambodia. Bilingual Khmer/English speaking, a few were Khmer reading. Educational attainment high school to bachelor's degree
Data collection location	Data were collected in the home or at the CBO, per participant request; most were completed in the home	Data were collected in the home	Data were collected in the home	Data were collected in the home, at the CBO, or at a community venue (e.g., church, clinic) per participant request; most were completed in the home
Data collected by LHR	24-hour urine sample	Interactive voice response system	Serial blood pressures	Sleep actigraphy Physical activity actigraphy Hair samples Trauma surveys
	Holter monitor	Continuous glucose monitor		

CALMS-D = community health workers assisting latinos manage stress and diabetes; CBO = community-based organization; CT, MA, RI = Connecticut, Massachusetts, Rhode Island; DREAM = diabetes risk reduction through eat, walk, sleep, and medication therapy management; LHR = lay health research personnel; RCT = randomized clinical trial.

included frequent check-ins with LHR to discuss activities and workload; there was daily quality assurance monitoring of research activities, daily communication with LHR about their workday, and weekly planning of research activities and assignment of LHR staff to conduct activities. There was regular review of documentation and data; provision of feedback on progress and performance; identification of training and resource needs; discussion of issues or challenges, such as burnout; and, commending LHR for accomplishments. Depending upon the nature of the supervision topic, supervision included real-time problem-solving between the supervisor and LHR, or scheduled one-on-one meetings, group LHR meetings, site-specific meetings, and meetings of the whole study team. The group meetings allowed for peer support and exchange of ideas among LHRs and between LHR and supervisors as well as constructive feedback and problem-solving.

Systems and equipment used by CALMS-D LHR to collect measures are in Table 3. They included Remote Electronic Data Capture (REDCAP [18]), an interactive voice response (IVR) telephonic survey system, a continuous glucose monitor, 24-hour urine samples, and a Holter monitor. LHR also obtained serial blood pressures during experimental challenges (sit-to-stand and handgrip challenges) as per Low 1993 [19]. Investigators and their staff trained LHR (ABM, CB, JW) or oversaw the training (RL, RPE) and provided supportive supervision during the fieldwork (SSP).

To examine LHR fidelity to data collection procedures, an independent, bilingual observer completed protocol compliance checklists while observing LHRs who were instructing a subset of 7 CALMS-D participants (3 women & 4 men, 53–75 years old, Spanish speaking, low income, low literacy). Percent compliance with the checklists was used to ascertain degree of fidelity with each checklist which ranged from 29 items for IVR to 48 items for CGM (see supplemental material #2). Field notes of subjective observations were also reviewed.

To examine LHR perspectives, the same independent observer conducted in-depth, semi-structured interviews with LHRs. LHR interviews each lasting from 1.3h to 2h. Content analysis was used to analyze qualitative data [20]. The Hispanic Health Council IRB approved the LHR observations and interviews.

Study #1 Results

CALMS-D Trial Participants

The *n* = 121 CALMS-D trial participants were 73% women, mean age = 60 (SD = 12) years old; most identified as Puerto Rican (71%), and nearly all preferred Spanish (93 %); 42 % reported eighth-grade education or less and 52% indicated their reading was "fair," "poor," or "cannot read at all." The majority (58%) were unemployed due to disability. The sample is described in detail elsewhere [21].

Table 2. LHR training in the CALMS-D and DREAM studies

Study	Hours	Topics	Training materials	Training methods
		Human subjects protection		
CALMS-D DREAM	3	What is research, research ethics, principles of human subject protection, the role of the institutional review board, and informed consent	Harvard Catalyst	Presentation, discussion, case studies
CALMS-D DREAM	2	Privacy, confidentiality, and data protection practices	Harvard Catalyst	Presentation, discussion, case studies
CALMS-D DREAM	3	Documenting informed consent, authorization of HIPAA, and permission for release of information	Harvard Catalyst	Presentation, discussion, case studies
		Research methods		
CALMS-D DREAM	2	Protocol, standardization, recruitment, screening	Study manual	Presentation, discussion
CALMS-D DREAM	2	Study design, randomization, personnel roles, supervision, meetings, documentation, emergency procedures	Study manual	Presentation, discussion
		Data Collection – Biological		
CALMS-D DREAM	3	Anthropometrics, BP	Scale, stadiometer, blood pressure cuff	Demonstration, practice, online tutorial
CALMS-D	3	Experimental physical challenges (sit-to-stand, handgrip)	Dynamometer, BP cuff	Demonstration, practice
CALMS-D	1	Urine sample	Sample container, cooler	Demonstration, discussion
DREAM	2	Facilitating fasting blood samples at local laboratory	Online laboratory scheduler	Demonstration, discussion
DREAM	1	Hair sample	Scissors, razor, string, foil	Demonstration, practice, online tutorial
		Data Collection – behavioral		
DREAM	1	Instrumenting with actigraphy	Actigraphy devices	Demonstration, practice
		Data Collection – Survey		
CALMS-D DREAM	1	Standardization, establishing rapport, reading questions, voice personality, being non-judgmental, probing techniques, minimizing disturbances during home visits	Study manual	Presentation, observation, live practice
CALMS-D DREAM	1	Responding to participant distress, seeking supervision for participant suicidality, pacing, and knowing when to take a break, reschedule, or discontinue an interview	Study manual	Presentation, observation, live practice
CALMS-D	3	Training participants to use the interactive voice response system.	Study manual; IVR survey; headphones; cell phones	Demonstration, practice,
		Data Entry		
CALMS-D DREAM	2	Remote Electronic Data Capture (REDCap)	Tablet, paper forms	Presentation, discussion, live practice
		Sample Handling and Data Transfer		
CALMS-D DREAM	1	Coding, mailing, and tracking devices and samples	Study manual	Presentation, discussion
CALMS-D DREAM	1	Cleaning equipment, re-ordering supplies	Handout	Discussion
		Participant Safety		
CALMS-D DREAM	1	Protocols for out of range values (e.g., very high BP)	Study manual	Presentation, discussion
CALMS-D DREAM	2	Protocols for potential participant suicidality/self-harm	Handout	Presentation, discussion
		LHR Safety		
CALMS-D DREAM	1	Home visits, trust your gut, working in pairs, parking, protecting study equipment, emergency procedures	Study manual	Presentation, discussion
CALMS-D	2	Blood-borne pathogens	University online tutorial	Video, quiz

Table 3. Details of home-based measures

Method	Measure	LHR Protocol	Challenges
Interactive voice response (IVR) telephonic survey system twice daily for 7 days	Psychosocial experiences and exposures	LHR taught participants to respond to telephonic surveys about mood, stressors, and diabetes, twice daily for 7 days. The IVR survey was offered in English or Spanish. CHWs reviewed each question with participants who then practiced answering surveys. A cheat sheet was made available with easy-to-read instructions and pictures. CHWs called the participants several times over the 7 days to promote adherence to the protocol, answer questions, and resolve any problems. Participants were provided the phone number of the CHW to contact in case of any difficulties. Study cell phone and headphones were loaned to participants.	Participant burden; questions seem repetitive; needing a quiet place to answer phone survey; too busy to answer phone
24-h urine sample	Urine protein and catecholamine levels	LHR taught participants to collect and store a 24-hour urine sample that LHR picked up and transported to the university for analysis. Participants were given "hats" in which to urinate on the toilet and a bottle to collect their urine for 24 hours. The bottle required refrigeration in a cooler chest. A cheat sheet was made available with easy-to-read instructions and pictures.	Forgetting; unpleasant; urinating while away from home; not wanting to store urine in the refrigerator
Continuous glucose monitor for 7 days	Interstitial glucose measured every 5 minutes	LHR instrumented participants with a CGM and de-instrumented them after 7 days. A supervisor transferred the electronic data file to the university. Medtronic Minimed Gold (Northridge, CA) CGM detects levels from 40 to 400 md/dL in the interstitial tissue via sensor to a monitor every 10 s. Participants were blinded to CGM glucose readings to minimize reactivity. LHR inserted the sensor under the skin and trained participants how to calibrate it twice daily for 7 days. LHR phone calls reminded participants to calibrate and to troubleshoot. Participants were also given a pictorial guide and LHR phone numbers for difficulties. A cheat sheet was made available with easy-to-read instructions and pictures.	Fear of insertion; forgetting to calibrate; discomfort of sensor insertion; itching/discomfort at the insertion site; unpleasant in hot months and many participants have no air conditioning
Holter monitor for 24 hours	24-hour heart rate variability	LHR instrumented participants with a Holter monitor, de-instrumented them after 24 hours, and a supervisor transferred electronic data file to the university. 7-lead, 3-channel ambulatory electrodcardiograms were used. LHR prepped skin and then instrumented participants with 7-lead, 3-channel ambulatory ECG monitors (Holters). GE Medical (Milwaukee, WI) Marquette Series 8500 direct (amplitude-modulated) recorders. A cheat sheet was made available with easy-to-read instructions. Participants were de-instrumented after 24 hours. Outcome was the standard deviation of the normal-to-normal R-R interval).	Itching/discomfort at electrode site; participant burden wearing the monitor and leads; no shower for 24 h; unpleasant in hot months and many participants have no air conditioning
Sit-to-stand blood pressure	Autonomic function.	LHR took digital blood pressure and recorded values in REDCap. The participant's blood pressure is measured with a digital sphygmomanometer by Ormron (Kyoto, Japan) while lying down, and again after standing up unaided. The postural falling blood pressure is taken as the difference in systolic blood pressure exactly 4 minutes after standing. Outcome is the Difference between the baseline supine and the minimal BP after standing up.	Protocol demands precision from LHR; need for quiet place to lie down
Handgrip blood pressure	Autonomic function.	The maximum voluntary contraction is first determined using a handgrip dynamometer. Handgrip is then maintained at 30% of that maximum for as long as possible, up to 5 minutes. BP is measured three times before and at 1-minute intervals during handgrip. The outcome is the difference between diastolic during handgrip and mean of 3 baseline diastolics.	Protocol demands precise timing from LHR; low participant motivation due to hand/wrist discomfort
Actigraphy for 7 days	Physical activity and sedentary behavior	LHR instrumented participants with two accelerometers, one worn on the hip and one on the wrist. After 7 days, LHR de-instrumented participants and a supervisor transferred electronic data file to the university. A tri-axial accelerometer (Actigraph GT3X, Actigraph) was worn for 7 days on the hip using an elastic belt or clip. Data collected at 80 Hz were downloaded (Actilife software, v6.13.3, Actigraph). Activity counts were analyzed at the minute level from the vertical axis of the device. Classification of activity was determined using cut-points to categorize minutes in sedentary behavior, light activity, and moderate-to-vigorous physical activity.	Participant burden and forgetting; accelerometer should not get wet

(*Continued*)

Table 3. (*Continued*)

Method	Measure	LHR Protocol	Challenges
Actigraphy for 7 days	Sleep	For the same seven days, participants wore an accelerometer (Actiwatch Spectrum Plus; Philips-Respironics, Murrysville, PA) on the non-dominant wrist. Outcomes included mean nighttime total sleep time (TST), mean nighttime wake after sleep onset, standard deviation of 24-h TST, and standard deviation of sleep timing (clock-hour midpoint for nighttime sleep).	Participant burden and forgetting
Hair cortisol	Chronic stress	LHR collected, packaged, and labeled hair samples and shipped them to the university for processing.	Participant concerns about esthetics and appearance
		LHR collected a hair sample (1 cm, ~ 1month of growth) from approximately 2 cm below the cranial bone.	
Surveys	Trauma symptoms	LHR administered surveys verbally and recorded responses in REDCap.	LHR discomfort asking, and participant distress responding to, items regarding trauma and hardship.
		16-item Harvard Trauma symptom questionnaire, 13 items from the *baksbat* questionnaire, 1 item regarding *kmoach sangkhat*, 4 questions regarding history of starvation, and the 6-item food security survey.	

CALMS-D = community health workers assisting latinos manage stress and diabetes; CGM = continuous glucose monitor; DREAM = diabetes risk reduction through eat, walk, sleep, and medication therapy management; IVR = interactive voice response; LHR = lay health research personnel; REDCap = Remote electronic data capture.
For example: "on a 3-point scale (1= "*not at all*" to 3 = "*a lot*") *did you . . . have pain, numbness, or tingling in your hands, legs or feet?*." Participants who did not own their own phone were provided study phones. All were provided headsets to facilitate hands-free keypad responding. Participants were provided with a "cheat sheet" of response options. IVR reporting windows were set for 8-10 AM and 8-10 PM. The IVR system called participants at random times during these 2-hour windows. If the call was unanswered, the system continued calling regularly within the time window. Participants could use a keypad response to indicate that they should be called back in 15 minutes. Postponed calls were permitted until the end of the reporting window after which the report was coded as missing.

CALMS-D LHR

Among the $n = 3$ LHRs, age ranged from 38 to 61 years, they were all bilingual and bicultural (2 Puerto Rican, 1 Peruvian). All were high school graduates; one had some college, another was taking college courses, and the other was a certified nursing assistant. One was a certified Community Health Worker. They were all extensively trained and provided with mentoring supervision throughout the CALMS-D trial.

Direct Observation

In direct observation of LHR with actual participants, fidelity to protocols was > 95% for each measure (see supplemental material). The observer notes stated that LHRs were all clear, empathetic, and displayed a high degree of technical skill, self-confidence, and patience. LHR were also observed to be skilled listeners, able to establish a trusting relationship of mutual respect, and display an effective use of time and effective implementation of protocols during home visits.

In-Depth Interviews with LHR

In interviews, LHR reported varying levels of challenge with each assessment but reported that the CALMS-D protocols, training, and supervision had been highly supportive and empowering. See Table 4 for topics, content, and representative quotes. LHR reported becoming very knowledgeable of the study protocols and successful at applying them: "*A kink here and there but we always solved it.*" They reported and feeling empowered to conduct their work: "*it is excellent what you learn in that field*" "*they give you different training to make you confident in your job.*" They reported feeling well trained: "*. . . lot's of training . . . I learned something new.*." They appreciated supportive supervision "*. . . if you have a question they look for an answer quickly.*" "*she is always asking to see my point of view.*" Facilitators of LHR success included being highly motivated and satisfied with their job, being detail-oriented, well-focused, patient, empathic, safety conscious, and a good communicator.

Study #2 Methods – DREAM

For the DREAM study (see Table 1), UConn Health was the lead institution providing scientific direction, fiscal oversight, and reporting to the sponsor (NIH). Recruitment was through two non-profit CBOs, Khmer Health Advocates and the Center for Southeast Asians. The Principal Investigator (JW) had a longstanding, trusting relationship with Khmer Health Advocates which facilitated DREAM, again, an important relationship for effective community-engaged research. LHR were employees of one of these two CBOs. Some LHR were existing employees and others were hired specifically for this study. The position posting can be seen in the Supplemental materials. LHR conducted home visits for data collection. The study coordinator was a bilingual, bicultural employee of Khmer Health Advocates who assisted in many aspects of the study. All DREAM procedures were approved by the UConn Health Institutional Review Board (IRB; #11-065-6). The CBOs did not have their own IRBs and relied on UConn Health.

DREAM was a randomized trial comparing three interventions for reducing diabetes risk among Cambodian Americans with depression (NCT02502929). The three interventions were all delivered by lay health workers: social services vs group lifestyle sessions vs group lifestyle sessions plus sessions with a pharmacist. This population came to the US as refugees who had survived trauma, torture, and forced starvation during the genocidal Pol Pot regime.

LHR Training

DREAM LHR were trained in research methods, human subjects protection, and study-specific data collection procedures. See Table 2 for details of training. LHR training followed the same principles for low-literacy learners as described above for CALMS-D. LHR training was spread across several weeks with homework

Table 4. Topics, examples, and quotes from in-depth interviews with LHR in the CALMS-D study

Topic	Content	Representative quotes
LHR training	Written protocols were helpful; keep instructions simple; training helped LHR anticipate problems; very good quality training; in-person with live models; protocols were explained clearly; LHR were trained how to motivate participants	" . . . they [investigators] made sure everything was there and they explained you" "[the study] gives me everything I need." "they give you different training to make you confident in your job" "they do excellent, they give you the practice"
Supervision of LHR fieldwork	Quick and supportive supervision was available to LHRs; support was always available; feel very secure contacting the supervisor; supervisor's disposition was helpful; supervisors want LHR to feel well and be safe	" [my supervisor] is very good . . . she would get in contact with the right person [to fix a problem]." " . . . if you have a question they look for an answer quickly." "she is always asking to see my point of view"
Technical aspects of devices and equipment	Tools/Equipment were easy to clean and maintain; have all equipment clean and ready to go; understand key specific challenges for each device and problem-solving strategies	"A kink here and there but we always solved it." "Know what to do if you get an error [message on the device]." "clean, disinfect everything" "put them [sharps] in the red container"
New skill acquisition	First time; new experience; involved in a different experience; learned how to take blood pressure; learning about research; knowledge previously, new learning; learning to listen; how to organize and deal with people	" . . . lot's of training . . . I learned something new." "it is excellent what you learn in that field"
LHR comfort and safety during home visits	Go in pairs; go in a car; park in a good place; wear gloves; be respectful	" . . . always aware of surroundings for safety." "safety is always first for me" "I always check my surroundings"
Facilitators of LHR success	LHRs are motivated; LHRs are satisfied with their job; well trained; detail-oriented; focused; patient and understanding; empathic; good communicator; calm, patient, reliable, not anxious	"You need to like what you do. My job is busy but not boring." "You need to pay attention to what you do." "Once you have everything ready you go with the flow . . . you need to make it happen."
Would you recommend this LHR position? Why/why not?	Yes. To know about research and the community; giving service and getting experience; learn something new; contact and interaction with people	"learning. [the study] helped me grow" "It's a way to experience something new, to learn about research."
Importance of trust with participants	Talk calmly; provide encouragement; explain why it's important for the community; ask how they're feeling; be friendly; be respectful	" . . . once you build that trust they feel comfortable around you." "I call them ahead to let them know I'm coming over so that they can prepare mentally . . . Give them the time." "Need to check up on them . . . I think it's the contact, the communication." "We have open communication and we call back and forth."
Participant training and understanding	Participants understood protocols; need to verify their understanding; they followed protocols; cheat sheet and wallet card for devices; instruction in their language; frequent communication; equipment ready for them to use	"Always communicate, explain to them [participants] what we are doing. It's very important." "I leave them everything they need to follow the protocol. I highlight things, explain them everything." "Always give a cheat sheet to participants . . . to remind them." "Sometimes they say they understand but in reality they didn't. Break it down for them." "Always have to explain . . . you have to do the recap"
Participant challenges	Hard for participant to follow protocol when out of the house or in an emergency; not being able to shower for 24 hours and itchy skin from the Holter; tired; home not always conducive to data collection	"Very compliant unless they are not feeling well that day." "They may miss a day because of their work schedules"
Participant motivation	Proper informed consent; appropriate incentives; incentives calibrated to compliance; LHR understand the challenges of the protocol; LHR understand the health status of the participants;	"I let them practice until they felt comfortable and could do it on their own." "they want to know their blood pressure"
Participant satisfaction	Satisfied to be included in the study; glad for incentives; grateful for the financial incentive; feel important to be part of the research; want to know their results	"They're thankful to participate." "Doing it [the study] shows the power they have." "They like someone coming to the house . . . they like that."

and practice between training sessions. Training included a manual designed for this study based on the CALMS-D manual. (The DREAM manual can be requested from the author or found at https://health.uconn.edu/diabetes-research/community-based-research/). Training also included several online tutorials such as an online video that demonstrated proper technique for hair sampling. LHRs learned directly from the investigators in their respective field of expertise. For example, a sleep researcher (OB) trained them in sleep actigraphy. The bilingual study coordinator (SK) was critical to all trainings. LHR observed and role-played data collection. For each measure, LHR were provided a clear rationale for the measure and its relevance to the community's health. LHRs conducted a minimum of 10 supervised assessments with structured feedback and were judged to be competent by the study coordinator prior to working independently. Supervisor field notes of these assessments were captured for qualitative

impressions of the interviews. Investigators (MS, SK, TK) supervised the fieldwork and were available to LHR throughout the study. LHR were awarded paper certificates in recognition of their completion of this training.

A psychologist (JW) trained LHR in administering sensitive surveys. This included topics such as understanding the nature and content of each question, interviewing the correct participant, reading questions as written, voice personality, establishing rapport, being non-judgmental, pacing an interview, probing techniques, knowing when to take a break, responding to participant distress, and participant self-harm safety protocol. Difficult situations and challenging cases were presented. LHR were also taught to work efficiently, record the response correctly, and properly document data. Importantly, because LHR may have personally experienced some of the sensitive situations they were assessing in others, time was spent allowing LHR to discuss their personal reactions to the questions and their comfort level asking them and recording responses.

Supervision

Supervision included on-demand phone calls between the supervisor and an LHR experiencing problems in the field. Regularly scheduled supervision included occasional one-on-one meetings, monthly site-specific group meetings, and meetings of the whole study team. Cross-site group meetings were facilitated by videoconferencing, but at least twice per year CHWs from across the tri-state area met in-person. These meetings, which included refreshments, were an opportunity for the LHR to discuss challenges, successes, provide peer support, socialize, and boost camaraderie. As in CALMS-D, supervision meetings were a time to discuss activities and workload; review documentation and data; provide feedback; identify needs, discuss challenges, and commend progress and accomplishments.

In DREAM, we shifted our focus to the proportion of missing/refused/declined/unusable data from the baseline assessments conducted by LHR. We calculated these outcomes for key behavioral and biological assessments as well as sensitive survey questions that might have a greater likelihood of missing data.

Behavioral data included physical activity actigraphy that entailed wearing a monitor on a strap around the waist, like a belt, as well as a watch-like sleep actigraphy device on the wrist for 7 days [22]. Validity criteria for sleep and physical activity methods have been detailed elsewhere [23]. For our purposes, three 24-hour periods of actigraphy data were considered acceptable for analyses; any fewer were considered missing. Participant burden with wearing devices can yield high rates of missing data. Finally, participants provided a hair sample, approximately the diameter of a pencil lead, from the back of the head for assessment of cortisol, a biomarker of chronic stress [24]. Participant concern about esthetics can result in high refusal rate for the procedure or inadequate hair samples for assay.

Highly sensitive psychosocial surveys included personal history of starvation during the Pol Pot genocide and current symptoms of trauma [22]. We also asked survey questions about Khmer culture-bound symptoms including *baksbat*, which uses folk idioms to describe a condition similar to post-traumatic stress disorder and *kmoach sanghkat*, a sleep disturbance related to trauma that describes sleep paralysis. LHR also assessed food insecurity [25], the discussion of which can be distressing to participants, particularly those with a history of starvation [26].

Study #2 Results

DREAM Trial Participants

In the DREAM study, the $n = 188$ participants were 78% female, average age of 55 years, nearly 50% had a household income below $20,000, most (64%) were not working, and the average educational attainment was 7 years. All spoke Khmer; only 54% were proficient in reading and 43% in writing in Khmer. They were on average 16 years old in 1979 at the end of the 4-year Pol Pot regime and $n = 120$ reported being emaciated during Pol Pot. At baseline, over half (54%) had elevated depressive symptoms and about one-third were taking antidepressant medication. The sample has been described in detail elsewhere [24].

DREAM LHR

The seven LHRs were all born in Cambodia and were bilingual/bicultural. They included a man in his 60s with one year of college who was a pastor at an Asian church; a woman in her 30s with a high school diploma who was a certified nursing assistant; a man in his 40s who had previously been a Buddhist monk; a woman in her 50s with a high school diploma who worked as a medical assistant; a woman in her 30s with a certificate in human service assistance, a woman in her 50s with a bachelor's degree who was an insurance agent; and a woman in her 60s with high school education who was the only certified Community Health Worker. All were active and trusted in their communities and were recruited through informal networks across Connecticut, Massachusetts, and Rhode Island.

Data Quality

Missing data for sensitive survey questions are as follows: household food insecurity 2.7%; symptoms of post-traumatic stress disorder 1.5%, *baksbat* 1.5%, *khmaoch sangkhat* 1.5%, and starvation during Pol Pot 11.6%. The percentage of participants with < 3 days of valid sleep actigraphy (i.e., coded as missing) was 3.7%, physical activity actigraphy 8.5%, and the percent with < 3 days both sleep and physical activity was 8.5%. Hair samples for assessment of cortisol were missing or insufficient for 7.5%.

Qualitative impressions from supervisors showed that DREAM LHR demonstrated a high degree of cultural consonance including respect for elders, using kinship terms, and use of cultural idioms. They also followed culturally dictated interpersonal etiquette such as rules for bowing, greetings, touch, removing shoes before entering the home, using both hands to pass an object to an elder, and avoiding head and feet. They conveyed respect for traditional medicine and healers and responded skillfully to participant fear of disclosure, mistrust of authority, and distress regarding trauma history.

Discussion

In these 2 trials, the work of LHR was highly successful. CALMS-D documented that fidelity to assessment protocols was high and that LHR found the work to be rewarding and empowering. DREAM showed acceptable levels of missing data for biological, behavioral, and highly sensitive psychosocial data (1.5%–11%). This compares favorably with a median of 9% missing *outcome* data in a recent review of RCTs in top medical journals [27]. Although we do not have data in this regard, it was our observation that missing data were more likely on the few occasions when LHR did not have access to REDCap and collected data using paper and pencil. Clear training, written protocols were deemed as helpful. LHR reported

that clear training and written protocols were helpful for their task and that clear communication and trust with participants lead to high participant motivation and satisfaction. To achieve these successful outcomes, the research team provided extensive training and supportive supervision and strived to create a culture of collaboration. Due to the relatively small literature on LHR specifically, in our discussion we rely on the broader literature on LHW, i.e., including those in non-research roles.

Training and Skill Acquisition

Overall, LHR enjoyed learning research skills, consistent with other reports [28]. Opportunities for training are considered crucial for LHW career development [29]. There are few studies of LHR, but qualitative data from LHW in clinical work show that, in addition to higher wages, a primary factor considered for LHW career advancement should be participation in additional training opportunities [29].

Methods for training in CALMS-D and DREAM were varied but in both instances they were rigorous and systematic. In addition to the specific data collection protocols, time was spent on education regarding the research enterprise more generally and how it differs from more traditional LHW tasks such as patient navigation and medical translation. As has been discussed by others [30], both trials offered LHR training in the principles of research ethics, i.e., respect for persons, beneficence, and justice as well as protection of human subjects and informed consent taking into account the required time for personnel naïve to research. In-person practice with live feedback from supervisors was critical. Understanding the rationale behind each measure, not simply the technique to collect it, was important to LHR.

LHWs are best motivated by work that provides opportunities for personal growth and professional development, irrespective of the direct remuneration and technical skills obtained [31]. One systematic review found that LHWs were empowered by access to privileged medical knowledge, by linking LHWs to the formal health system, and by providing them an opportunity to do meaningful and impactful work [32]. However, these empowering influences were frustrated by lack of control over one's work environment and feelings of being unsupported, unappreciated, and undervalued. We believe that our success was from pairing the empowering factors – knowledge, linkage to a formal system, and meaningful work – with appropriate remuneration and supportive training and supervision, all of which demonstrated appreciation and valuing of LHR.

Notwithstanding their broad set of skills, there were some data collection procedures that LHR did not conduct. We experienced that LHR were comfortable shipping material samples, including hair samples and actigraphy supplies. However, whereas they were comfortable *collecting* electronic data (i.e., from Holter monitor, CGM), they were not comfortable *transferring* the electronic data to the university over the Internet. Based on their understandable discomfort with the technological complexity of data transfer and potential for loss of confidentiality, we had supervisors transfer electronic data.

Collaboration

Working relationships between LHWs, health professionals, and community members strongly shape LHW motivation [31]. We aimed for a collaborative relationship shown to be key in previous studies. In Uganda, 8 LHWs in two tuberculosis clinics formed a community of practice [33]. In qualitative interviews, LHWs identified activities as core to improving the quality of their work: (1) individual review of performance, (2) collaborative improvement meetings, (3) real-time communications among members, (4) didactic education sessions, and (5) clinic-wide staff meetings. LHWs reported that these activities allowed them to share challenges, exchange knowledge, engage in group problem-solving, and benefit from social support. They felt a shared sense of ownership of the work, which motivated them to propose and carry out innovations. The model community strengthened their social and professional identities within and outside the group and improved their self-efficacy. Whereas neither CALMS-D nor DREAM created a formal community of practice, our meetings were mostly successful in including the key elements including collaborative improvement, feedback, real-time communication, education, and study-wide meetings.

A concrete example of collaboration was the number of ways LHR brought real-life experience to develop acceptable methods. They pilot-tested all the measures, both biological and surveys, and provided feedback about challenges and potential solutions. For example, LHR helped us calibrate incentives that were motivating but not coercive for community members. They suggested bringing coloring books and crayons to home visits to keep children in the household occupied. They suggested that we provide headsets for answering the IVR telephone calls, and recommended coolers for urine storage because participants were not comfortable storing it in the refrigerator. They informed the handouts that we gave to participants for each measure. Another example of collaboration is the co-creation of tracking documents that were designed by LHR with ease of use in mind and by researchers with data elements in mind. Our bilingual, bicultural study coordinators were extremely helpful in facilitating these types of LHR input.

Although LHRs were involved in data collection, recruitment, and intervention delivery in CALMS-D and in DREAM studies, they did not collaborate on research design *per se*. Nevertheless, it should be noted that both studies were community-based, participatory research studies and the academic and CBO personnel worked together as "equal partners" to identify the problem, develop a research question, and design and conduct the study.

To recruit and retain LHR, human resource policies of the hiring institution must be considered [34]. It was our experience that LHR being employed by the CBO, rather than the university, was ideal. Participants associated LHR with the CBO, an organization known trusted and located in the community, rather than with the university. Their direct supervisors at the CBO managed their scheduling, which can be complicated when some LHR are paid part-time on the study and part-time in service delivery programs. Recruiting, interviewing, hiring and firing LHR, and internal communications are facilitated by the CBO. Also, a CBO may be more likely than a university to have a position available once the grant funding ends, so a CBO can offer LHW more job security.

Supervision

Availability of prompt and helpful support for fieldwork was reported as helpful and necessary, consistent with prior literature. In one study, a group supervision intervention was implemented in 4 African low- to middle-income countries (LMICs [35]) and then 153 in-depth interviews with LHWs, their supervisors, and managers. In addition, questionnaires assessing perceived

supervision and motivation were administered to a total of 278 LHWs pre- and post-intervention, and again after 1 year. Although questionnaires showed no quantitative changes, qualitative findings showed perceived value in the process of supervision, the problem-solving focus, the sense of joint responsibilities and teamwork, cross-learning and skill sharing, as well as the facilitating and coaching role of the supervisor. The empowerment and participation of supervisees in decision-making also emerged as important.

A study in Uganda [36] conducted focus groups with four high/medium-performing CHW teams and four low-performing LHW teams. Variances in scores between "high"-/"medium"- and "low"-performing LHW teams were largest for "supportive supervision" and "good relationships with other healthcare workers." LHW team performance was related to the quality of supervision and relationships with other healthcare workers. Key supervisor issues included absentee supervisors and lack of engagement/respect.

In Zimbabwe, $n = 342$ government-employed LHWs were tasked with identifying and referring pregnant women for early antenatal care [37]. Factors associated with performance of one task were not the same as those associated with performance of another task, but both tasks depended on type and quality of supervision.

We submit that providing ongoing, supportive supervision to LHWs is critical. We found that tools such as checklists were helpful for LHR task completion and that simple spreadsheets were key for tracking progress with, for example, study assessment visits. We encouraged LHR to co-create these tools so that they would be of maximal benefit to the team. According to the Rural Health Information Hub [15], a supportive LHW supervisor is regularly available, provides supportive and trauma-informed supervision, prioritizes safety, and offers monitoring and coaching to LHWs. It is also essential that the supervisor dedicates sufficient time for LHWs, especially those working in new roles.

Limitations and Conclusions

Several limitations should be considered. First, the sample of LHRs was small and limited to only two racial/ethnic communities in the New England region of the U.S. Second, in this article we used different methods to examine LHR performance across these two studies, mainly fidelity in CALMS-D and missing data rates in DREAM, so we cannot compare them directly. However, evidence previously published shows that CALMS-D LHR collected high-quality data with few missing values [21] and DREAM LHR were also able to successfully perform clinical measurements [24]. Although the researcher conducting the LHR qualitative interviews was an independent third party, the study coordinators giving subjective impressions were not, and researcher bias and demand characteristics cannot be ruled out.

Notwithstanding these limitations, this work confirms our previous work on LHR and data collection in type 2 diabetes self-management interventions including DIALBEST [38]. Similar lessons regarding training, supervision, acceptability, motivation, and support from the broader team have been described regarding CHW providing service delivery [39]. The role of the bilingual, bicultural study coordinators in working with LHR on each aspect of the study was crucial. It should be underscored that CALMS-D and DREAM were not just facilitated by LHR, but were in fact completely dependent upon them [40]. LHR helped the academic researchers develop data collection protocols that would have the greatest likelihood of acceptability to participants and LHR also helped investigators anticipate and avoid potential mistakes, inefficiencies, and cultural misunderstandings. LHR feedback about problems with data collection procedures and potential solutions were vital. Further, this relationship of mutual respect may mitigate LHRs acting as gatekeepers to research, i.e., acting to "protect" patient populations from experiencing trauma by engagement in research [41].

LHR possess a unique skill set that makes them indispensable members of the research team, rather than mere "helpers" that facilitate task shifting downwards [42]. Home-based data collection of this nature would be difficult or impossible by a typical academic researcher embedded in an academic research setting.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/cts.2023.647.

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References

1. **Phillips K, Müller-Clemm W, Ysselstein M, Sachs J.** Evaluating health inequity interventions: applying a contextual (external) validity framework to programs funded by the Canadian health services research foundation. *Eval Program Plann*. 2013;**36**(1):198–203.
2. **Varma DS, Strelnick AH, Bennett N, Piechowski P, Aguilar-Gaxiola S, Cottler LB.** Improving community participation in clinical and translational research: CTSA sentinel network proof of concept study. *J Clin Transl Sci*. 2020;**4**(4):323–330.
3. **Hohl SD, Thompson B, Krok-Schoen JL, *et al.*** Characterizing community health workers on research teams: results from the centers for population health and health disparities. *Am J Public Health*. 2016;**106**(4):664–670.
4. **Taylor B, Mathers J, Parry J.** Who are community health workers and what do they do? Development of an empirically derived reporting taxonomy. *J Public Health (Oxf)*. 2018;**40**(1):199–209.
5. **Varma DS, Samuels E, Piatt G, *et al.*** Community health workers and promotoras' perspectives of a research best practice course: a focus group study. *J Clin Transl Sci*. 2022;**6**(1):e137.
6. **Gaziano TA, Abrahams-Gessel S, Denman CA, *et al.*** An assessment of community health workers' ability to screen for cardiovascular disease risk with a simple, non-invasive risk assessment instrument in Bangladesh, Guatemala, Mexico, and south Africa: an observational study. *Lancet Glob Health*. 2015;**3**(9):e556–e563.

7. **Musse Jde O, Marques RS, Lopes FR, Monteiro KS, dos Santos SC.** [Assessment of competencies of community health workers for epidemiological data collection]. *Cien Saude Colet*. 2015;**20**(2):525–536.
8. **Lopes FRL, Monteiro KS, Figueiredo T**, ***et al.*** Reliability of information on people with disabilities gathered by community health workers in highly consanguineous communities of Northeastern Brazil. *BMC Health Serv Res*. 2017;**17**(1):317.
9. **Allen CG, Brownstein JN, Cole M, Hirsch G, Williamson S, Rosenthal EL.** Building a framework for community health worker skills proficiency assessment to support ongoing professional development. *J Ambul Care Manage*. 2018;**41**(4):298–307.
10. **Wagner J, Bermudez-Millan A, Damio G**, ***et al.*** Community health workers assisting Latinos manage stress and diabetes (CALMS-D): rationale, intervention design, implementation, and process outcomes. *Transl Behav Med*. 2015;**5**(4):415–424.
11. **Wagner J, Armeli S, Tennen H**, ***et al.*** Diabetes self-care behaviors, and continuously monitored glucose: a daily study of Latinos with Type 2 diabetes. *Psychosom Med*. 2017;**79**(7):798–805.
12. **Bermudez-Millan ASK, Feinn R, Perez-Escamilla R, Segura-Perez S, Wagner J.** Food insecurity is associated with autonomic dysfunction among latinos with Type 2 diabetes. *Curr Dev Nutr*. 2020;Jun;;**4**:162.
13. **National Institutes of Health**. *Clear Communications*. Rockville Pike, Bethesda, Maryland: National Institutes of Health, 2021 (https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication) Accessed October 25, 2023.
14. **EuroMed Info**. *Designing Low Literacy Materials*. United Kingdom: European Sources Online Cardiff University, (https://www.euromedinfo.eu/designing-low-literacy-materials.html/) Accessed October 25, 2023.
15. **Rural Health Initiative Hub**. *Supervising and Supporting Community Health Workers*. Grand Forks, ND: Rural Health Information Hub, School of Medicine and Health Sciences, 2020 (https://www.ruralhealthinfo.org/toolkits/community-health-workers/4/supervising-and-supporting) Accessed October 25, 2023.
16. **Centers for Disease Prevention and Control**. *Behavioral Risk Factor Surveillance System Interviewer Training Module*. 2011. Centers for Disease Control and Prevention Public Health Surveillance and Informatics Program Office Division of Behavioral Surveillance, Atlanta, GA. Accessed October 25, 2023.
17. **Puerto Rican Elderly Health Conditions (PREHCO)**. *Manual del Entrevistador*. Universidad de Puerto Rico and University of Wisconsin-Madison, 2003 (https://prehco.rcm.upr.edu/sites/default/files/website_pdf/Ent2.pdf) Accessed October 25, 2023.
18. **Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG.** Research electronic data capture (REDCap)–a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;**42**(2):377–381.
19. **Low PA.** Composite autonomic scoring scale for laboratory quantification of generalized autonomic failure. *Mayo Clin Proc*. 1993;**68**(8):748–752.
20. **Hsieh HF, Shannon SE.** Three approaches to qualitative content analysis. *Qual Health Res*. 2005;**15**(9):1277–1288.
21. **Wagner JA, Bermudez-Millan A, Damio G**, ***et al.*** A randomized, controlled trial of a stress management intervention for Latinos with type 2 diabetes delivered by community health workers: outcomes for psychological wellbeing, glycemic control, and cortisol. *Diabetes Res Clin Pract*. 2016;**120**:162–170.
22. **Wagner J, Bermudez-Millan A, Berthold SM**, ***et al.*** Psychological distress and health behaviours among Cambodian Americans at risk for developing diabetes. *Stress Health*. 2023;**39**(2):372–383.
23. **Master L, Nye RT, Lee S**, ***et al.*** Daily temporal associations between sleep and physical activity in adolescents. *Sci Rep*. 2019;**9**(1):7732.
24. **Wagner JA, Bermudez-Millan A, Buckley TE**, ***et al.*** Community-based diabetes prevention randomized controlled trial in refugees with depression: effects on metabolic outcomes and depression. *Sci Rep*. 2023;**13**(1):8718.
25. **Bermudez-Millan A, Feinn R, Hanh C**, ***et al.*** SNAP participation moderates the association between household food insecurity and A1c among Cambodian Americans with depression. *Ethn Health*. 2021;**27**(7):1718–1731.
26. **Wagner J, Bermudez-Millan A, Berthold SM**, ***et al.*** Exposure to starvation: associations with HbA1c, anthropometrics, and trauma symptoms four decades later among Cambodians resettled in the USA. *Int J Behav Med*. 2023;**30**(3):424–430.
27. **Bell ML, Fiero M, Horton NJ, Hsu CH.** Handling missing data in RCTs; a review of the top medical journals. *BMC Med Res Methodol*. 2014;**14**(1):118.
28. **Klein KG, Tucker CM, Ateyah WA**, ***et al.*** Research interests, experience, and training of community health workers: a mixed method approach. *J Community Health*. 2022;**47**(6):949–958.
29. **Smithwick J, Nance J, Covington-Kolb S, Rodriguez A, Young M.** Community health workers bring value and deserve to be valued too: "key considerations in improving CHW career advancement opportunities. *Front Public Health*. 2023;**11**:1036481.
30. **Terpstra J, Coleman KJ, Simon G, Nebeker C.** The role of community health workers (CHWs) in health promotion research: ethical challenges and practical solutions. *Health Promot Pract*. 2011;**12**(1):86–93.
31. **Colvin CJ, Hodgins S, Perry HB.** Community health workers at the dawn of a new era: 8. Incentives and remuneration. *Health Res Policy Syst*. 2021;**19**(Suppl 3):106.
32. **Kane S, Kok M, Ormel H**, ***et al.*** Limits and opportunities to community health worker empowerment: a multi-country comparative study. *Soc Sci Med*. 2016;**164**:27–34.
33. **Hennein R, Ggita JM, Turimumahoro P**, ***et al.*** Core components of a community of practice to improve community health worker performance: a qualitative study. *Implement Sci Commun*. 2022;**3**(1):27.
34. **Hill MN, Bone LR, Butz AM.** Enhancing the role of community-health workers in research. *Image J Nurs Sch*. 1996;**28**(3):221–226.
35. **Kok MC, Vallières F, Tulloch O**, ***et al.*** Does supportive supervision enhance community health worker motivation? A mixed-methods study in four African countries. *Health Policy Plan*. 2018;**33**(9):988–998.
36. **Ludwick T, Turyakira E, Kyomuhangi T, Manalili K, Robinson S, Brenner JL.** Supportive supervision and constructive relationships with healthcare workers support CHW performance: use of a qualitative framework to evaluate CHW programming in Uganda. *Hum Resour Health*. 2018;**16**(1):11.
37. **Kambarami RA, Mbuya MN, Pelletier D, Fundira D, Tavengwa NV, Stoltzfus RJ.** Factors associated with community health worker performance differ by task in a multi-tasked setting in rural Zimbabwe. *Glob Health Sci Pract*. 2016;**4**(2):238–250.
38. **Pérez-Escamilla R, Damio G, Chhabra J**, ***et al.*** Impact of a community health workers-led structured program on blood glucose control among Latinos with type 2 diabetes: the DIALBEST trial. *Diabetes Care*. 2015;**38**(2):197–205.
39. **Pallas SW, Minhas D, Pérez-Escamilla R, Taylor L, Curry L, Bradley EH.** Community health workers in low- and middle-income countries: what do we know about scaling up and sustainability? *Am J Public Health*. 2013;**103**(7):e74–82.
40. **Lu JJ, D'Angelo KA, Kuoch T, Scully M.** Honouring the role of community in community health work with Cambodian Americans. *Health Soc Care Community*. 2018;**26**(6):882–890.
41. **Killough CM, Madaras A, Phillips C**, ***et al.*** Community health worker insights on promoting research engagement with diverse populations. *Front Public Health*. 2022;**10**:959504.
42. **Berthold SM, Kong S, Kuoch T**, ***et al.*** Combating health disparities in Cambodian American communities: a CBPR approach to building community capacity. *Prog Community Health Partnersh*. 2017;**11**(2):109–118.