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- 4 The quest for diffusible community health worker projects and the pitfalls of scaling
- 5 culture

Researchers of community health worker (CHW) models in many countries are looking for ways to scale without losing one of their main advantages, their context-sensitivity. This paper looks at one research strategy to make CHW projects scalable, namely by developing a generic notion of culture-sensitivity. Based on in-depth qualitative analysis, we reconstruct how 'culture' has been enshrined in a US-based CHW project and specifically in the artefact of a binder with teaching materials for vulnerable mothers. The inscription of generalized, culture-sensitive spaces into the binder did allow the Project to comply with standards of evidence-based medicine while respecting community self-determination and made space for creative and competent CHW practices. Yet at the same time, it took away from more substantive conceptions of community engagement and from community empowerment through CHWs. Our analysis highlights how the focus on culture can invisibilise and displace the importance of

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competent CHW practice and processes of community engagement.

Community health workers (CHWs) are important health service providers in resource-constrained communities around the world (Ramirez-Valles 2003; Swartz and Colvin 2015; Torres et al. 2017). Made prominent through the 1970s turn to Primary Health Care in international health institutions, CHWs deliver essential services in many low-and middle-income countries, but also in high-income countries such as the United States. While their activities and working conditions vary across organizations and settings, health scholars and practitioners agree that CHWs are important due to their proximity to underserved

communities, their credibility with those communities, and thus their anchoring in concrete socio-cultural contexts (Rosenthal et al. 2014; Wallace, Farmer, and McCosker 2018). Still, while valuing this context-sensitivity, researchers and policy makers also keep searching for evidence of 'what works' in CHW projects (World Health Organization 2018). Therefore, CHW proponents strive to develop models that can be scaled and diffused across sites, in ways that both preserve their strength of being flexible and context sensitive, and offer best practices for diffusion (Bradley 2018).

One site of search for best practices is the US, where CHWs are experiencing a veritable 'boom' (Kangovi and Asch 2018) spurred by a surge of research on CHWs since the 1990s, networking among CHW activists, and growing attention by policy makers (Torres et al. 2017). This culminated in the 2020 announcement of US President-elect Joe Biden to add 150,000 CHW jobs (Biden Harris Democrats 2021) to the estimated 56,000 CHWs in the country (U. S. Bureau of Labor Statistics 2018). Community health worker models appear promising to US policy makers as a comparatively low-cost workforce that can address the growing concern with health inequity and the social determinants of health (Kangovi and Asch 2018). Yet, this does not mean that CHW models are clearly defined or firmly established. Activists, scholars, and practitioners debate funding, organization, community ownership, and, importantly, the right kind of evidence: What makes a good CHW intervention that should be scaled?

In this paper, we focus on pluralism and conflict between public health epistemologies as a major challenge for the CHW movement. We conducted an in-depth qualitative study to explore how researchers design a CHW intervention that satisfies competing epistemologies. As in other fields of health research and interventions, e.g., debates about top-down or bottom-up design of complex interventions (Greenhalgh and Papoutsi 2018; Hawe 2015, 311), researchers of CHW models are torn between different epistemological conceptions of good research. They participate in the search for 'gold standard' evidence in line with evidence-based medicine (EBM), while also respecting community knowledge and participation and thus the standards of community-engaged research (CEnR) (Rosenthal et al. 2014; Wiggins et al.

2009). EBM norms favor the scaling of standardised interventions that have been tested in an RCT, CEnR norms demand the responsiveness of interventions and interveners to the researched communities, and ask for context sensitivity rather than standardisation (Haapanen and Christens 2021). Alignment with EBM matters as research funders or public health programs favor interventions that satisfy the epistemological demands of EBM (Parkhurst and Abeysinghe 2016). At the same time, public health research increasingly seeks to value community knowledge and thereby CEnR, in efforts to reverse hierarchies in research practice. Against this backdrop, our research project set out to explore how CHW projects manage to adhere to both EBM demands for standardized evidence and CEnR demands for contextual fit and asked: How can these two epistemologies be reconciled to design interventions that are transferable but also sensitive to concrete communities, respecting those communities' agency (see Logan 2019)? What can function as a scalable core of CHW models that finds support by both CEnR and EBM?

We studied an instance where a US-based maternal health project has proven productive in satisfying the needs of both EBM and CEnR, (from here on, 'the Project') to understand how health projects can navigate such epistemic pluralism. The effectiveness of the Project has been proven with an RCT just as it has been informed by community knowledge. The Project works with community health workers to support young mothers. The CHW intervention has been established by an academic centre in an indigenous US community (from here on, 'the Center'). Our in-depth qualitative analysis of the Project is informed by Science and Technology Studies (STS) and thus attentive to the role of material artefacts.

We found that the Project has designed 'boundary objects' that are valued by the epistemologies of EBM and CEnR. Boundary objects enable bridges and collaboration between different epistemologies as they are flexible enough to be interpreted and utilized differently (Star and Griesemer 1989a). Like many home-visiting CHW projects, this intervention rests on a core technology, a binder with teaching materials. Such binders structure programmes, the stages that the CHWs and their clients move through,

¹ We use community-engaged research (CEnR) as a generic term for community-based participatory research and participatory action research (see Baum 2016).

and the contents that should be delivered to the clients (e. g. Miller 2014). Our analysis established the binder of the Project as a boundary object that makes it possible to do research validated both by the epistemologies of EBM and CEnR. We find in our in-depth qualitative study that the binder's reference to culture makes it possible for the Project to be valued by both epistemologies. We show that the inscription of a generic notion of culture into the binder enabled its boundary work and the validation of the Project both by CEnR and EBM. Therewith, this article reconstructs one strategy to reconcile context-sensitivity and scalability in CHW projects with a generic notion of culture-sensitivity.

Culture is a contentious concept in the health sciences, since it is often used to designate 'Others' – non-white, non-middle-class groups whose behaviour is deemed irrational and therefore risky (DiGiacomo 1999; Fox, Thayer, and Wadhwa 2017; Jones 2011). In contrast, we show how the use of culture can instead be a strategy to navigate epistemic pluralism in public health. Still, we highlight the costs that come with such strategy of reconciling EBM and CEnR in the discussion. The generic notion of culture can invisibilise and displace the importance of competent CHW practice and processes of community engagement. This is not the only strategy to reconcile contexts and interventions. Others focus on iterative approaches, where bottom-up participatory design is followed by scaling and generalization and then possible recontextualization for novel fields (Greenhalgh and Papoutsi 2018; Kangovi et al. 2016). Complexity thinking reassesses the linear claims of RCTs and distinctions between core and variable dimensions of interventions (Greenhalgh and Papoutsi 2018; Hawe 2015). We discuss the analysed strategy of bridging medical epistemologies with boundary objects in the light of such alternative strategies.

In the remainder, first, we introduce the challenges of CHW programs to move between EBM and CEnR. The reconciliation of such distinct epistemologies is a concern beyond the analysed Project. Second, we present the methods, and third the results of our study. We highlight that reconciling CEnR and EBM with 'culture' rests on creative and pragmatic compromises from the viewpoint of both epistemologies. In the discussion, we explore to what extent making culture the bridge within such a compromise can have problematic implications.

Community-engaged research meets evidence-based medicine

Our study illustrates a strategy of linking influential epistemologies of medical research whose tensions and hierarchies are widely debated. On the one hand, CEnR consolidated during the last decades. Its adherents strive to conduct health research that involves and respects the communities that are researched, taking guidance from the norms of community-engaged approaches such as community-based participatory research (CBPR) (Haapanen and Christens 2021). According to CEnR epistemology, knowledge from affected communities is of similar value as knowledge produced by medically trained experts. Practitioners of CBPR and related methods such as participatory action research combine ideas from action research, Latin American liberation theory and the radical pedagogy of Paulo Freire, into community-engaged research practice (Loewenson et al. 2014). Its epistemology demands that researchers and community members interact in a deliberative manner while determining the goals and means of the research project (Baum 2016; Minkler and Wallerstein 2003). These epistemological norms are designed to overturn established power relations in medical research and induce transformational social change by including the researched individuals as co-researchers (Baum 2016).

CBPR's emphasis on community empowerment aligns with CHWs' self-understanding as agents of change instead of mere medical implementers (Wiggins et al. 2009). This self-understanding has been underlined through several nation-wide CHW professionalization initiatives stressing advocacy and community organizing as core CHW activities (C3 Project 2016; Rosenthal 1998). For these reasons, CBPR has been used to develop and refine CHW interventions in many Latin American and US settings (Wiggins et al. 2017). In the context of Native communities, where the Project originated, a range of institutions seek to guarantee community co-decision – also and importantly as a reaction to gross historical abuses of medical research in minority communities (NCAI 2012). Native community review boards oversee the research process and have the authority to set parameters for research foci and outputs (Brugge and Missaghian 2006; LaVeaux and Christopher 2009). Indigenous CBPR stresses community values and knowledge and recognizes tribal sovereignty and self-determination (Walters et al. 2020).

In parallel, since the 1990s, the epistemic standards of EBM have become authoritative for researchers, practitioners and policy makers (Timmermans and Berg 2010). In the epistemology of EBM, the most highly valued medical models are those whose impact on health indicators are supported with RCTs (Wieten 2018). This so-called gold standard of EBM increasingly becomes guidance for policy makers who seek to support health care models with a strong evidence base (Rodrigue and Reeves 2015). Even though the quest for a 'controlled' research context and the hierarchical positing of EBM are controversial (Parkhurst & Abeysinghe, 2016), health interventions that can be evaluated through RCTs have an advantage when it comes to applying for research funding, given that many grant calls by funders such as the NIH request conducting an RCT. A model supported by successful implementation of EBM protocol can also be sanctioned as a best practice model that can be scaled. For example, for CHW models on child rearing, a model which aligns with the demands of EBM becomes eligible for federal US funding schemes for infant and child health.

Tensions between both epistemologies have been widely debated, although the diversity in community-oriented approaches warrants against oversimplification (Haapanen and Christens 2021). Some scholars regard CEnR as a method to adapt the results of EBM to communities (Katz et al. 2011), assuming that all valuable medical knowledge must be supported by RCTs (Hawe 2015, 316). Others challenge such an instrumental view of CEnR as 'being in the service' of EBM (Trickett 2011, 1353). CEnR, from this viewpoint, should rather be about overcoming the hierarchies between academic knowledge produced with EBM, and community knowledge (Haapanen and Christens 2021, 334–335). Scholars also describe practical obstacles in combining EBM and CEnR in CHW research. RCTs' strict focus on measurable outputs limits communities' ability to influence the research, and long-term and complex effects of CHW services are difficult to capture through RCTs (Rosenthal et al. 2014, 241).

Methods and data

The analysed Project was selected as a case for in-depth qualitative examination as it managed to comply with the epistemologies of both CEnR and EBM. We studied the Project to understand strategies that make it possible to gain acceptance from such distinct epistemologies. The Project was designed in compliance with CBPR standards and closely collaborated with community boards to incorporate input from community members, for example, by recruiting mothers from the community as liaisons to the Native advisory boards. It also managed to receive grants from the NIH due to its evidence-based design. The project demonstrated positive effects on a broad set of behavioural health indicators for both mothers and children through RCTs and its rollout was therefore endorsed in federal funding schemes. The Project is considered a best practice within the field, with the potential to diffuse globally. In the analysis, we will show how the Project aligns with more general trajectories and scaling strategies within the CHW field, bridging demands from EBM and CEnR.

The paper draws on secondary and grey literature on the US CHW movement, publications and webinars of CHW associations and projects, and on semi-structured interviews with CHWs, CHW project leaders, and advocates from field visits to CHW projects in seven US states. We have interviewed 24 individuals about the broader politics of the CHW movement, and validation through research amidst competing epistemologies emerged as an important theme in these interviews. On the Project, we interviewed and gathered background information from ten individuals closely related with the Project and the Center. Here, we interviewed experts on administration of federal funds to utilize the binder; members of organizations utilizing the binder; employees conducting field research for the binder and a similar project; the project manager concerned with the binder at the Center; the current head of the Center, who is also the current principal investigator for research on the binder; the retired founder of the Center; and experts on CBPR in the context of the Project, focusing on its navigation of EBM and CEnR. We have changed the names of the protagonists and their institution. We reviewed all the academic articles published on the

binder, newspaper articles, an organizational history of the Center, and a PhD thesis on the binder. The transcripts have been edited to aid their readability.

Analysis

Our interpretation is based on a close reading of the analysed material and interview transcripts. In accordance with our research question, our interpretation of the material explored the theme of how both epistemologies feature in the work and self-representation of actors engaged with the Project. Our interpretive focus builds on perspectives and concepts from science and technology studies (STS). STS scholarship has been concerned with epistemology as the social practice of knowledge production, the role of material artefacts in the socio-academic coproduction of research, and analyses the social inscriptions and roles of these artefacts (Shaffer 2021). Such a focus has been adopted by public health research that explores the productive role of artefacts such as leaflets for research projects (Loblay et al. 2020). Taking from the conceptual toolbox of STS, we explored while analysing our material how materially sedimented boundary objects enable work between both epistemologies (Star and Griesemer 1989b). Boundary objects contain the flexibility to enable collaboration between different epistemic communities without a consensus between these communities (Clarke and Star 2008). We examined to what extent the binder can be interpreted as a materially sedimented boundary object that achieved agreement from the epistemologies of EBM and CEnR.

Results: Culture as medicine

In many respects, the Project achieved the best in terms of CEnR and EBM, with a community-based intervention design and a standardized effectiveness test allowing scaling of the intervention. We found that the culture-sensitive binder served as a bridge between EBM and CEnR. In the Project, the binder is designed to be physically placed between the CHW and the young mother, showing teaching material to the CHW and illustrative contents to the mother. The Project utilizes several binders for different modules. The CHW proceeds from one module to the other, carrying the latest module to her visits.

The binder was designed over several decades, initially developed in a Native American community. It has been endorsed by the Indian Health Services and exported to non-Native settings as well. Currently, the binder is utilized by dozens of organizations across the US and preparing to be diffused internationally. It plays an important role in the diffusion of the Project: The Center sends boxes with the binder to CHW programs who apply the Project. A closer look at the binder's validation reveals, though, that the alignment with both branches of medical research comes at a cost: The binder has not incorporated specific cultural practices or context elements as core to the intervention, 2 nor validated CHWs' impact on health outcomes.

Negotiating the meaning of culture

How did the binder manage to be validated both by EBM and CEnR? Our study shows that the inscription of 'culture' into the binder enabled its acceptance in terms of both epistemologies: The culture-sensitive binder served as a bridge between EBM and CEnR. The Project started from an approach to culture mobilized in the field of behavioural health, for example, anti-addiction programmes. It states that culture can be a positive resource for healthy behaviours since the stability and sense of identity enshrined in communities and shared traditions can fend off destabilizing forces at play in modern societies. In line with CEnR, the focus of the Project is on mobilizing or restoring inherited cultural practices that can empower and enhance health, for example traditional parenting practices, forms of physical activity, and healthy traditional foods (Trainer A, cited in a report on the project).

The focus on traditions with a potential to enhance health resonates not only with discussions in social epidemiology about resiliency-enhancing and protective features of culture, for example, where family orientation may protect individuals against risky behaviours (Castro, Barrera, and Martinez 2004). It also aligns with the philosophical underpinnings of CBPR and its Freirian popular education roots. According to CBPR, community members are the foremost experts on the challenges they face and on the resources that they have to address these challenges. CEnR entails the promise to 'disrupt traditional

² See Hawe on the intricacies of defining core versus variable elements of interventions (Hawe 2015).

hierarchies built around academic and expert knowledge' by bringing community knowledge into dialogue with academic research (c.f. above) The binder makes space for tapping these resources by designating placeholder spaces in the teaching session – blank sections in the curriculum where programs and CHWs can bring in cultural lessons – to support cultural reflection and thus creative CHW practice.

At the same time, the Project referenced culture in a manner that enabled acceptance by EBM. Initially, to make such practices part of a scalable intervention in line with EBM, the Project strived to name and measure them. Yet, this turned out to be difficult. A researcher of the Project explained to us the challenge of defining 'cultural lessons' in a manner that is compatible with the demands of both EBM and CEnR:

Researcher: In the very earliest days, we tried to have lessons about the local culture. And then the elders in the community said: 'You don't write that stuff down, but you leave places for it in the curriculum'. So basically, there are prompts in the curriculum that say, if your community has traditions around the birth of a baby, this would be a good time to talk about that. Or if your community has certain things that you do, certain beliefs about breast-feeding, this would be a good time to talk about them. Because when we wrote them down, they were never exactly right. It's like an oral heritage and people wouldn't say it in English the same way and it just got kind of I think when they read it on paper it looked awkward compared to just letting this be part of the relationship-building and say it in your own language.

The Project thus sought to refrain from fixing the meaning of living cultures. But additionally, it had to take into account the diversity of culture, as the Researcher also stressed:

Researcher: So now the Project got sort of proven in communities in [name of a region](...) but when it started, we got a lot of demand to scale it to different areas that have different languages, different cultures. And basically, what we then did was [that] we had sort of a template to say 'Here are all the places in the curriculum where these cultural inputs are, there is space for your cultural inputs'. And some communities actually create their own 'co-guide' for that whereas others just use the prompts to do it. (...)

Interviewer: Very interesting. Is it right to say that you got these blank spots for everything which is not directly medical?

Researcher: Yes, exactly. It is nothing that we consider the core elements or anything that related to our outcomes. But maybe these other things enhance engagement. We know the relationship between the [CHW] and the mom is really important for engagement and retention. So, these things are really

important for that. And then we also, from a lot of other work we have done, know that strong cultural identity is associated with less substance use, more resilience, better mental health. So, all these things might be having secondary effects on the long-term health of the families. Never ever may we be able to measure that (...). (Interview researcher)

The curriculum of the binder thus tried to facilitate enactments of culture, but in a way that respects the fact that subgroups vary. For the Project, uniform descriptions of cultures by outsiders do not do justice to these communities, thus adhering to CEnR norms (see NCAI 2012). Yet at the same time, the high value that EBM places on measurable and standardisable interventions meant that cultural practice could not become a 'core element[s]' (see above). Rather, it became necessary to work with templates and prompts for culture to inscribe cultural knowledge into the binder. 'Never ever' can the importance of cultural knowledge be measured and be validated by EBM. The inscription of a generic notion of made it possible to do both: Value community knowledge in line with CeNR and ensure validation of the binder by EBM.

The result is that the interpretation of culture is left to the CHW and her clients while utilizing the binder and encountering the gaps in the curriculum. As a consequence, does the Project confer it to the agency of CHWs to tap the value of culture? Does CeNR trump EBM as community knowledge is core to the Project?

Community health workers – cultural agents?

During the research process, the Center worked with Native CHWs to recruit personnel they considered trusted members of the community. They are the workforce whose agency fills in the blank spot for 'culture' left in the Project design. According to a trainer:

So the para-professionals, we really capitalize on the strength of them. So they know the culture, oftentimes they're from the community. They're very familiar with the local resources. They're very familiar with who to contact in local community partners. They can relate to what our families are going through, oftentimes they've been through it themselves. A lot of our families may already know them and may already feel comfortable with them. Para-professionals also eliminate the cultural and

language barriers that may exist for non-Native home visitors. So they're at the very core of our program. (Trainer A, cited in a report on the project)

Hence, the cultural competences of CHWs feature prominently in the Project philosophy. Yet, aligning this philosophy with EBM led to a rather limited role for CHW agency. In designing the RCTs, the Center did not prove the effectiveness of CHWs per se. In the trials, the treatment group consisted of CHWs using the binder, whereas the control group consisted of CHWs without a binder. The difference that CHWs make has not been subject to evaluation, only the difference that the binder makes for CHW practice, an instance of silencing relational labour also observed in other behavioural health interventions (Wolters et al. 2020). The individual professional contribution of CHWs was thus not validated in the intervention study, so that in the trial the object – the binder – and not the subject – the CHW – constitutes the intervention.

Bracketing CHW agency has been the price of fidelity and protocol adherence that is needed to perform RCTs (Mehta et al. 2019; Rosenthal et al. 2014). Had CHWs used the curriculum too flexibly, trial results might have been meaningless as they could have lacked internal validity. This was exactly what had happened in the first trial, as CHWs had deviated from the binder. To attain robust results, the Center subsequently made sure that protocol was followed. The Center conducted extensive trainings on protocol adherence, tested the CHWs' knowledge for the faithful delivery of the intervention and engaged in regular supervision and phonographic recording of all sessions. Certainly, as we have shown in the previous section, protocol adherence also means filling the spaces left for enacting cultural strengths. Yet, given that these blank spots are not spelled out in the binder, and neither is the agency of CHWs subject to the trial, the Project's core and scaled component are the standardized teaching materials. Cultural competency remains an assumed background condition.

Discussion and conclusion

This paper discussed the quest for scalable CHW interventions in the light of epistemological pluralism. We analysed the construction of a binder with lessons for young mothers, to be taught by CHWs, and how it reconciled CEnR and EBM norms. We demonstrated how this binder references cultural competences of CHWs and showed that using culture as a bridge between EBM and CEnR draws attention to strengths of communities and CHWs. Still, the need to measure and standardise scalable elements meant that the binder referenced culture only as a placeholder for assumed interactions. While CHWs' cultural competences were assumed through these placeholders, the CHWs' contribution to the Project's success was not evaluated. In the discussion, we focus on the consequences of this cultural interpretation of CHWs' agency for the broader CHW movement.

While this is only one project with its unique history and contribution in public health, it does give reason to suspect that counting on culture – be it cultural fit, cultural traditions, or strengths – is not sufficient to harness the promise of CHW models and of CEnR approaches to act on the social determinants of health and work towards health equity (see Torres et al. 2017). Many CHW advocates, not only in the US, are sceptical of a medicalization of CHW's work, fearing that their integration into standardised medical (if not disease-specific) interventions curtails CHWs' ability to engage in advocacy and broader sociomedical work (Druetz, Ridde, and Haddad 2015; Nading 2013). Invocation of culture does recognize non-biomedical aspects of CHW work, and can broker consent from EBM and CEnR. For example, a focus on culture makes the binder agreeable for funding organizations that value RCTs just as for community review boards. Yet, the emphasis on culture might detract from other valued traits of CHWs such as advocating for social change and identifying structural barriers to good health (c. f. Malcarney et al. 2017; Warr, Mann, and Kelaher 2013). It circumscribes CHWs as carriers of cultural identities, while the community CHWs act for and with is often a community of experience and practice and not a linguistic or ethnic community. As recently stressed by a national community health worker leader, CHWs act 'based

on the need, the shared close experience of individuals, and oftentimes that crosses culture and ethnicity' (GHSM Proseminar 11, 24'11''-26'10'').

Probing and validating a fuller set of CHW practice in a way that both recognizes community ownership and thus CEnR, and the need for standardized evaluation and thus EBM, will require linkages beyond the generic notion of culture. We have shown that such linkages are usually compromises with mediating boundary objects allowing some ambiguity. Such compromises broker consent both from researchers who aim for alignment with RCTs just as from community representatives. Still, a more direct operationalization of community engagement practices and CHW activities, developed in collaboration with CHWs (see Rodela et al. 2021), promises to probe and diffuse a more comprehensive set of CHW contributions to public health.

Finally, as a strategy to design interventions that matter across sites while remaining flexible for situational adjustments, boundary objects address similar sensitivities as complex interventions (Hawe 2015). With boundary objects, the compromises and negotiations demanded by such an intervention are neatly packed into the standardized object, allowing for evaluation with RCTs. On the other hand, the inscription of complexity into the object means silencing the challenges of designing a complex intervention. Diffused as fixed intervention elements, the compromises between RCTs and CEnR are no longer visible and adaptation is no longer part of the intervention design. In contrast, a complex intervention problematizes the need for continuous readaptation. As long as RCTs are highly valued, public health interventions will face such trade-offs when incorporating contextual elements.

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