Community-Based Participatory Research to Promote Health Equity Among Sexual and Gender Minorities in the US South: Research Laureate Address

Scott D. Rhodes, PhD, MPH, FAAHB

Abstract

Sexual and gender minorities (SGM), including lesbian, gay, bisexual, transgender, and queer (LGBTQ+), communities, continue to face profound health disparities in the United States and globally. Although the terms SGM and LGBTQ+ are used as umbrella terms, the populations they describe are highly diverse. Currently, SGM persons are increasingly open and visible in the United States and many other parts of the world, and a modest body of knowledge on the health and well-being of some SGM subgroups currently exists. However, significant gaps exist in the emerging knowledge base, and there remains a profound need to promote health equity and reduce disparities. I am committed to advancing health behavior research to promote health equity and reduce disparities using community-based participatory research (CBPR) approaches. In this paper, based on the address I gave at the Scientific Meeting of the American Academy of Health Behavior (AAHB) on April 14, 2024, I describe what inspires me, a few things I have learned so far, and my future directions as I continue to partner with SGM communities to address health equity and reduce health disparities.

Keywords: Sexual and gender minority, CBPR, intervention, methods, health behavior research, HIV, transgender, Guatemala

* The corresponding author may be reached at: SRhodes@wakehealth.edu

Introduction

Being selected as Research Laureate of the American Academy of Health Behavior (AAHB) is a tremendous honor, as it is the highest member award bestowed by the Academy. Candidates for this award are evaluated on several criteria, including the overall quality of publications, funding, quality of mentoring activities, service to the community, and the impact of their scholarship on the field (https://aahb.org/ResearchLaureate_Past). I am immensely grateful to the Academy for this recognition, and such recognition, at least in my case, is the result of the passion and commitment of members of the teams I work with currently and those I have worked with previously. These teams are comprised of research staff (including those working on specific research studies and those behind the scenes supporting the pre- and postaward efforts), students and postdoctoral trainees, early career faculty mentees, co-investigators, federal partners, and other colleagues who push my science forward with their own advancements and discoveries.

I have been privileged to work with a core team of research staff for over a decade. They propel our science through their etic and emic perspectives, critical thinking, commitment to social justice, and dedication to communities. Members of the team include or have included: Sandy Aguilar-Palma, LLM; Jorge Alonzo, JD; Manuel Garcia; Elias Arellano Hall; Lilli Mann-Jackson, MPH; Raquel Mendieta; Jaime Montaño;

Lucero Refugio Aviles; Rodrigo Rodriquez-Celedon; Eunyoung Y. Song, PhD; and Aaron Vissman, PhD.

Furthermore, the research I am part of is only "award-worthy" because of the community partners I am privileged to work with. Over the past two decades, numerous community members and representatives from community organizations and health departments have trusted me and my team. They serve as inspiring partners, including representatives from the Alliance of AIDS Services – Carolina, an HIV service organization in Raleigh, NC; El Pueblo, a Latine-serving organization in Raleigh, NC; RAIN, an HIV service organization in Charlotte, NC; Triad Health Project, an HIV service organization in Greensboro, NC; Western North Carolina AIDS Project (WNCAP), an HIV service organization in Asheville, NC; the NC Department of Health and Human Services; and local public health offices across NC, among other organizations.

Finally, despite how intense our passion for science is, we all have people supporting us. We cannot write research grants, conduct research, disseminate findings, and promote positive change without their support and the joy they bring to our lives. For me, I am most grateful for Glen Troiano, who contributes immeasurably to my happiness every day.

Having acknowledged many, but certainly not all, of those who contribute to the science I am part of, I want to emphasize that this is not an end-of-career address. I hope to have many years ahead, conducting robust research in partnership with community members, representatives from community organizations, service providers, and other researchers. I aspire for the research I am involved in to continue increasing in both innovation and impact over time.

Now, I turn to describing what inspires me, outlining a few things I have learned so far, and sketching where I think I am going as I continue to partner with SGM communities to promote health equity and reduce disparities. I hope that what I describe reminds others of their own passions, helps them connect the dots of their own experiences to fortify and continue their own research trajectories, and inspires them to think about how to apply their own health behavior research skills to promote health equity, reduce health disparities, and improve the trajectories of vulnerable and minoritized communities and populations.

What Inspires Me

I do not often get the opportunity to talk about my parents during a research talk, but they were huge inspirations. I am a blend of my dad, an academic and mechanical engineer, and my mom, a public health practitioner, environmentalist, and community activist. They instilled in me an appreciation of the importance science and evidence and the value of using knowledge to contribute to positive change. They were role models of applying knowledge generated to contribute to social, economic, and reproductive justice. Today, the research that I am part of focuses on intervention research, recognizing the need to promote individual, community, structural, and policy change to achieve health equity and reduce disparities.

The HIV epidemic has also contributed greatly to my focus. I was an undergraduate when then-US Surgeon General C. Everett Koop published and sent to every US household a brochure about HIV transmission (https://stacks.cdc.gov/view/cdc/6927). When I read the plea on the back page of the brochure for volunteers to provide education and support within their local communities, I felt a sense of duty to support other gay men. I volunteered for a local HIV service organization, which led me to continue to channel my community activism as an out

gay man into work as a health educator at the Whitman-Walker Clinic in Washington, DC, after I graduated. I quickly realized that the front lines were not for me; instead, I found my calling in addressing HIV research gaps through community engagement and partnership.

My service in the US Peace Corps was also pivotal. I served in Guatemala for three years, learned some Spanish, and witnessed extreme inequities based on socioeconomics, education, race/ethnicity, sexual orientation, language (indigenous Maya languages versus Spanish), and gender identity. This experience greatly expanded my worldview and deepened my commitment to change. While I did not have the words for it then, I was developing an understanding of the social determinants of health. After all, I could have been born in the mountains of rural Guatemala, and no amount of motivation or grit would have brought me to where I am today. Indeed, place matters.

Finally, communities inspire me. Community members, representatives from community organizations, including HIV- and Latine-service organizations, and service providers inspire me with their commitment and dedication to their friends, neighbors, and the communities and populations they serve. Their unwavering commitment motivates me to continue my work and strive for meaningful positive change.

Team successes

The teams that I have been part of and led as principal investigator have had some strong successes; I am proud of our work. We have developed, implemented, and evaluated more than 20 interventions in partnership with communities. These interventions include interventions designed to reduce sexual risk through condom use, HIV testing, screening for sexually transmitted infections (STIs), and pre-exposure prophylaxis (PrEP) use; increase engagement in HIV care; address social determinants of health (e.g., education, social support, discrimination, immigration, and employment); promote COVID-19 testing and vaccine uptake; enhance cervical cancer screening; decrease smoking; and improve access to needed care among some of the most minoritized populations, such as Spanish-speakers, immigrants, racial/ethnic minorities, sexual and gender minorities, and people with HIV. Through this research, we have made strides in improving health outcomes and promoting health equity for those who need it most.

Five interventions we developed in partnership with communities are part of the CDC *Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention*. They include: *ChiCAS* for Spanish-speaking transgender Latinas (Rhodes et al., 2024), *HOLA* and *HOLA en Grupos* for Spanish-speaking Latine GBQMSM and transgender women (Rhodes et al., 2020; Rhodes et al., 2017), *HoMBReS* for predominately non-gay/non-MSM Spanish-speaking Latino men (Martinez et al., 2014; Rhodes et al., 2009; Rhodes et al., 2016), and *weCare* for GBQMSM and transgender persons living with HIV (Tanner et al., 2018). These interventions build on the concept of natural helping. Natural helping refers to the spontaneous, informal style of social support provided organically by individuals or groups to others in their social networks or communities (e.g., friends and neighbors) (Eng et al., 2009). It occurs naturally when people ask for and offer help within their communities. Harnessing natural helping in health behavior research deserves further exploration and understanding, as it can significantly enhance the effectiveness of interventions and promote health equity.

Currently, our team is blending natural helping with mHealth within the *Appalachian Access Project* intervention. This intervention leverages the strong,

preexisting social networks of GBQMSM and transgender and nonbinary individuals. It is designed to meet the needs and priorities of underserved and minoritized communities in rural Appalachia through community-based peer navigation and mHealth. The intervention includes training GBQMSM and transgender and nonbinary persons to serve as peer navigators, known as "community health leaders," within their social networks. These community health leaders work to increase awareness of HIV, STIs, hepatitis C (HCV), and mpox (formerly known as monkeypox) and their prevention and care. They provide guidance on how to promote use of services, including PrEP, syringe services, and medically supervised gender-affirming hormone therapy (GAHT). Additionally, they help improve understanding of social determinants of health and enhance the ability to effectively communicate and apply social support strategies both in person and through mHealth social media (Rhodes et al., In press).

A Few Lessons Learned

There is nothing like a good logo.

As the team has developed, implemented, and evaluated behavioral interventions, I have learned several key lessons, a few of which I delineate here. First, there is nothing like a good logo. Logos are important for communities, participants, and teammates. They provide an image and thus a feeling for all partners and collaborators[*] to identify with and rally around. Our logos typically are designed by community members with review and back-and-forth discussion with project-specific steering committee members and CBPR partners. Depending on the needs of the project, the logo may be passed on for refinement by a professional artist. The artist may provide multiple versions of the logo for feedback depending on how refined the draft version is. This iterative process ensures the logo reflects community priorities and contexts, creating a unifying symbol for the project.

Not every SGM participant fits neatly into a categorical box.

When we wrote our grant application for our currently funded *Appalachia Access Project* intervention, we initially proposed to work with gay, bisexual, and other MSM and transgender women. However, after securing funding, our steering committee thought that our inclusion criteria were too narrow did not accurately reflect how community members identity. We learned that communities within the catchment area have nuanced ways of identifying, expressing a broader spectrum of identities intersect across race/ethnicity, sexual orientation, gender identity, and rurality (Sucaldito et al., 2023).

Our steering committee advised that broadening our inclusion criteria would establish trust and harness the strengths of existing social networks while reaching those at risk. Consequently, we refined our inclusion criteria to include persons who identify with one of a spectrum of identities, including gay, bisexual, and queer men and other men whose sexual partners include cisgender men and/or transgender persons, and transgender persons, including transgender women and men and nonbinary persons, whose sexual partners include cisgender men and/or transgender persons. As a result of this broader inclusion, one out of five participants in our study identifies as nonbinary. This is extraordinary; we would

[*] "Stakeholder" has negative connotations for some tribes and tribal members, and it is recommended that other terms be used in its place (https://www.cdc.gov/healthcommunication/Preferred_Terms.html).

not have achieved this representation or learned from this hidden group of participants if our steering committee had not been so astute and our team so inclusive, thoughtful, and creative.

Partnerships are critical.

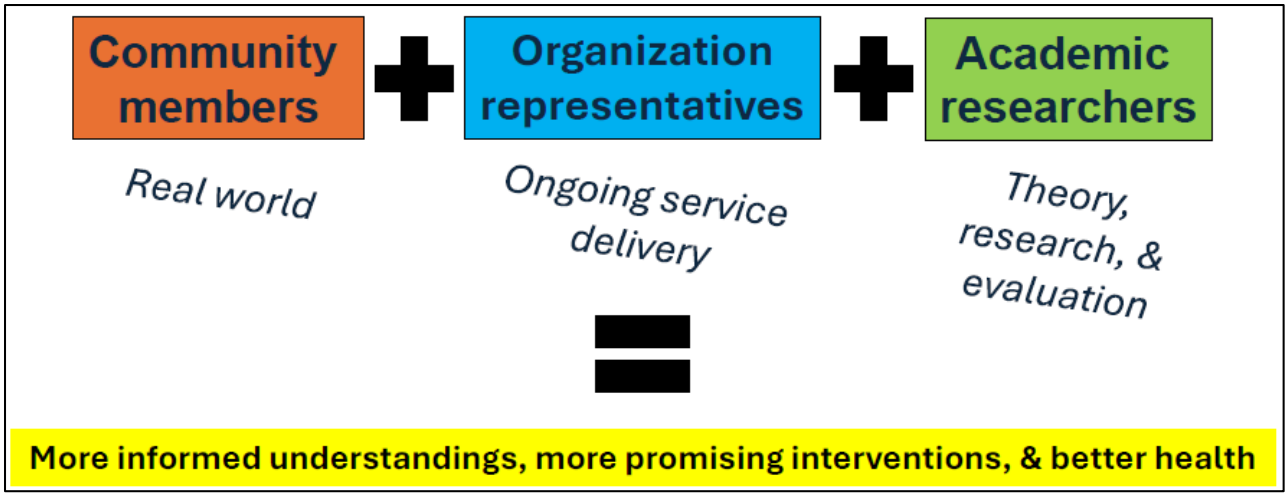
Partnerships are essential, requiring amazing talent from partners from multiple sectors to form, nurture, and maintain committed, authentic, and productive relationships among lay community members, representatives from community organizations, service providers, and academic researchers. We use CBPR partnerships, project-specific steering committees, and informal community networks throughout the research process — from formulating research questions; designing, conducting, and evaluating studies; to disseminating findings. Partnership harnesses the experiences, perspectives, and insights of diverse partners and collaborators. For example, community members provide real world perspectives and organization representatives and service providers provide insights based on ongoing service delivery. I like to remind others that as a researcher I have something to offer too. I bring expertise related to theory, research, and evaluation. Figure 1 provides a simple illustration of key contributions by partner type, and I contend that the research that is community-engaged and aligned with CBPR is much stronger.

Authentic partnerships that include a diversity of partners and collaborators across multiple sectors, in which there is trust and mutual commitment and understanding, lead to more informed understandings of health phenomenon. In turn, this more informed understanding results in the most the promising strategies to improve health.

Ask for help and be a problem solver.

Another lesson I have learned is the importance of asking for help. Afterall, we are all working to improve community and population health. Reach out to someone with more expertise, cold call a potential community partner, and share your story, your passion, and your commitment. We all benefit from varying perspectives, lots of advice, and the wisdom of experience throughout all phases of the research process. Additionally, I value problem solving. The team I work with does not see barriers as insurmountable; instead, we view them as

Figure 1. Abbreviated key contributions by partner type



challenges to figure out and overcome.

Communities are diverse, beyond what meets the eye.

Communities are inherently diverse, often in ways that are not immediately visible. When we consider diversity, we tend to focus on the obvious characteristics like age and skin tone. In the research I am part of, we also focus on sexual orientation and gender identity. However, diversity extends far beyond these dimensions. Numerous other factors based on identity and experiences significantly influence health behaviors, access to care, and quality of care, as examples. These factors include health status, marital status, insurance coverage, disability, HIV status, immigration status; educational attainment; parental or caregiver roles and responsibilities; living conditions (such as, rurality and household size); employment type and whether in multiple jobs; language use; and access to transportation, to name a few ways communities are diverse. Recognizing this broad spectrum of diversity is crucial when thinking about communities and exploring and addressing health behaviors.

Intervening before complete understanding is ok.

We cannot wait for complete understanding of health phenomenon and health behavior to intervene. Thinking we can wait until we have complete understanding of health phenomena and behaviors before taking action is impractical, as we will never possess all the data or information. Complete understanding is always elusive. We know this because contexts change and the dynamic interplay between individuals, behaviors, and environments, as highlighted by reciprocal determinism in social cognitive theory (Bandura, 1986). My team does not strive for complete understanding of health behavior; instead, we strive for sufficient understanding. If we are going to promote health equity and reduce disparities, we cannot merely study the phenomena; we must quickly apply knowledge, even incremental knowledge, to drive positive change.

Theory is critical! (Detail is critical!)

Speaking of theory, social and behavioral theory is critical. However, merely referencing theory is insufficient. It is essential to thoroughly integrate theories and demonstrate how their constructs are operationalized, especially in developing and testing interventions. For instance, in our *weCare/Secure* intervention, which is designed to reduce food insecurity among persons with HIV who are prediabetic or diabetic, we created a library of meticulously crafted sample mHealth social media messages that are organized by theoretical construct and by participant categorical needs, such as seeking a food resource such as pantries, applying for SNAP benefits, overcoming stigma related to food insecurity and/or HIV, and addressing challenges to preparing healthy foods. Health educators or interventionists use this message library to personalize messages for each participant based on theoretical constructs and individual needs (Tanner et al., 2022).

The work of health behavior research is challenging, but we continue to improve.

Making the world a better and healthier place through health behavior research is daunting. However, with each incremental stretch, each success, each challenge, and even each failure, we grow as scientists, teammates, partners, and team leaders. We also become better teachers, mentors, and colleagues.

My best science has yet to come (I assume and hope!).

Early in my career, I reminded myself that each project, intervention, and paper did not have to define my career. Afterall, I was developing skills that would ensure I would be stronger and better researcher over time. But is that not always the case? I recognize that my science will continue to improve. We continue to learn from both our mistakes and our successes, driving us forward.

Where I Think I Am Going

The upstream social determinants of health must be prioritized within research.

While the team, partners, and I have had some highly focused interventions to address pressing public health issues, the need for multilevel interventions to tackle social determinants of health is undeniable. Securing funding for research on such distal outcomes, however, remains challenging. It can be difficult, for example, to link the outcomes from an immigration policy intervention to changes on specific health outcomes such as PrEP uptake or HIV treatment adherence. Nonetheless, progress can be made by intervening on components of or proxies for upstream social determinants to positively influence health outcomes.

I contributed to the development, implementation, and evaluation of the *Impact Triad* intervention that was designed to increase STI screening, HIV testing, condom use, PrEP use, and knowledge of existing resources to address community-prioritized social determinants of health—employment, education, social support, and discrimination—among African American/Black and Latine GBQMSM and transgender women (Mann-Jackson et al., 2021; Robles Arvizu et al., 2023). While we did not change employment, education, social support, and discrimination, we took logical and sequential steps that were designed to initiate the process of moving the needle. I look at it this way: the initial response to the HIV epidemic focused heavily on education and awareness. Overtime the science of behavior change advanced, leading to well-articulated theories, strategies, and measures. Behavioral intervention science advanced profoundly and rapidly. Similarly, to address social determinants of health, we must take the initial steps that might include raising awareness of local resources among communities in need support and begin to systematically build the capacity of organizations to support minoritized communities. The science will undoubtedly advance, but we must take initial steps to set the foundation for more comprehensive interventions.

How can artificial intelligence (AI) be meaningfully harnessed in behavior change?

My team's research with mHealth social media began in the early 2000s with a focus on using online chatrooms that were used for social and sexual networking to educate GBQMSM about HIV and HIV testing. We initially used AOL chat rooms and Manhunt to provide details of about HIV and STIs, where GBQMSM could be tested, and what to expect when accessing testing and screening services at different types of venues (e.g., provider offices, free clinics, health departments, and HIV-service organizations). As social media and how people use social media evolved, we expanded to other platforms, including Adam4Adam, Grindr, Jackd, and Scruff, as well as texting.

In these interventions, we use a real, human health educators because we found that participants were more likely to engage with a real person who can authentically interact, help problem solve barriers in real time, and celebrate successes. Participants were more inclined to follow the desired behavior (e.g., attending a PrEP or HIV care appointment) when they felt a connection with a health educator. This personal touch made a significant difference, unlike the impersonal text reminders one might receive from a dentist, which lack support or concern. The question arises then, can AI replicate what a health educator does?

Impact is critical.

As I look down the road, I am keenly aware that many communities and populations continue to face profound health disparities, and I am committed to continuing to maximize the impact that the team and I are making to the health and well-being of some of our most vulnerable populations including SGM populations. We need more focus on research that is paradigm shifting, practice changing, and policy relevant, focused on the most vulnerable of communities and populations, such as SGM.

Another direction I hope to pursue involves global research, particularly in Guatemala. My team and I have successfully explored and identified the health needs, priorities, and assets, and developed effective interventions for some of the most vulnerable and minoritized populations in the United States, including Spanish-speaking GSM communities. We have also conducted formative research in Guatemala among SGM populations (Alonzo et al., 2016; Rhodes et al., 2014; Rhodes et al., 2015). Given these experiences, it makes sense for us to expand our research efforts to Guatemala, focusing on communities facing significant disparities. While Guatemala has made some progress in recognizing the rights and needs of SGM individuals, there is still a long way to go to achieve acceptance, equality, and health equity. This seems like an important area where I can make a positive impact.

Communities deserve the best science.

Finally, I remain committed to community-engaged research, including CBPR, to identify community needs, priorities, and assets and to develop authentic, assets-based interventions. After all, communities deserve the best science. Community-engaged research and CBPR maximize the probability that what we develop and do together as partners is based on what the community itself sees as priorities. This approach is more informed because it involves sharing broad perspectives, insights, and experiences. It builds the capacity of all partners to solve challenges, leverage community assets, and conduct meaningful research, and it promotes sustainability. My research will undoubtedly continue to rely on invaluable partnerships with community members, representatives from community organizations, service providers, and other academic researchers.

Conclusions

Advancing health behavior research to promote health equity and reduce disparities remains a multifaceted and deeply rewarding endeavor. My journey, inspired by personal experiences, community activism, and professional collaborations, has been guided by a commitment to addressing the unique needs of vulnerbale and minoritized populations through innovative, evidence-based interventions. My team's successes underscore the importance of community-engaged research and CBPR, leveraging natural helping, and harnessing mHealth

strategies to reach and support minoritized comunities and popualtions.

Being honored as the Research Laureate by the American Academy of Health Behavior is a testament to the collective efforts of dedicated research staff, community partners, and supportive colleagues (and friends). This recognition drives me to continue striving for excellence in health behavior research.

Communities deserve the best science. By acarefully applying CBPR, we ensure that our interventions are meaninful, informed by diverse perspectives, and sustainable. This approach builds the capacity of all partners, fosters meaningful research, and promotes lasting positive change. As I look to the future, I remain steadfast in my dedication to these invaluable partnerships, aiming to improve health outcomes and promote equity for all.

Thank you for this incredible honor, and congratulations to the members and affiliates of the Academy for their commitment to community and population health and their own successes in health behavior research.

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