Incorporating Community Member Perspectives to Inform a Resident Health Equity Curriculum

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ABSTRACT

Background There are few published resources to guide content of health disparities curricula. To train physicians to effectively address disparities, the needs and expectations of the local community need to be considered.

Objective To obtain community insight about factors influencing health disparities and important components of a health disparities curriculum for residents.

Methods This qualitative study consisted of 5 focus groups held in 2019; 4 included local community members, and the fifth was of leaders from local agencies serving these communities. Each focus group was professionally led and transcribed. Using an inductive approach to content analysis, the authors created codes from the transcripts. They then categorized the codes to support the development of themes.

Results Sixty-five community members participated in the 4 focus groups, and 10 community leaders participated in the fifth. Overall, 6 themes emerged from the data: (1) A healthy community is a community with access; (2) system-inflicted stress weighs heavily on health; (3) communities have internal strengths; (4) racism affects care delivery; (5) respectful bedside manner is necessary to build trust and better health outcomes; and (6) experience the community to learn and appreciate strengths and needs.

Conclusions This study illustrates that the community's input provides insights on what to include in a health disparities curriculum and serves as a model for incorporation of the community perspective in curriculum development.

Introduction

The seminal report Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare[1] detailed stark health disparities in the United States. Though 2 decades old, many of these health disparities (ie, health differences closely linked with social economic, and/or environmental disadvantage[2]) continue to exist. Since up to 75% of academic health centers (AHCs) are in underresourced communities,[3] it is imperative that AHCs are at the forefront of addressing these disparities.

One approach is through the education of trainees. Although several groups, including the Accreditation Council for Graduate Medical Education (ACGME), have called for increased focus on health disparities in training, a 2015 survey of internal medicine residents and program directors found that less than 40% reported a health disparities curriculum.[4] Additionally, the ACGME's Clinical Learning Environment Review team found that health care disparities education is often ad hoc and does not address the specific populations served by the institution,[5] thereby leaving "substantive deficiency in preparing residents and fellows to both identify and address disparities in health care outcomes, as well as ways to minimize or eliminate them."[5]

Historically, attempts by AHCs to address these disparities are unidirectional with minimal input from the community.[6] Only by engaging the community perspective can a meaningful and effective understanding of the social drivers of health be obtained,[7,8] as without their input, valuable knowledge and insights would necessarily be omitted.[6,9,10] Although prior studies have explored the use of patients and the public in medical education,[11-15] to our knowledge, no prior study has directly queried community members for their input on a health disparities curriculum, and few[16] have involved community members in the problem identification and general needs assessment step of Kern's approach to curriculum development.[17] Therefore, the aim of this study was to explore: (1) the local community's perspective about contributors to and protectors against health disparities and (2) the community perspective about what residents should learn about these in a health equity curriculum.

DOI: http://dx.doi.org/10.4300/JGME-D-23-00373.1

Editor's Note: The online version of this article contains the focus group moderator guide.

Methods

Study Design and Conceptual Framework

Using theoretical concepts underpinning community-based participatory research (CBPR)[18]—namely the

importance of partnering with the community to ensure the integrity of the work—we used a constructivist paradigm[19] to better understand the social reality and human experiences of local community members. This approach allowed us to add the perspective of the local community to a completed literature review and resident needs assessment as first steps in the creation of a 3-year longitudinal health disparities curriculum for the 141 pediatric residents at our large, urban program located in Washington, DC. Focus groups were chosen for the study design to give community members an opportunity to build ideas based on the insights and experiences being discussed.[20]

KEY POINTS

What Is Known
Incorporating community input is key to reducing health care disparities, but how best to link input with curriculum development remains poorly understood.

What Is New
This qualitative study of community members at risk for experiencing health care disparities revealed 6 themes they recommend be considered in curriculum design.

Bottom Line
Readers designing curricula addressing health care disparities should ensure these 6 themes are incorporated into the content.

Setting and Participants

Between April and August 2019, we conducted 5 focus groups to elicit community members' expertise for the curriculum development process. Based on the work of Malterud et al,[21] we a priori determined that 5 focus groups would give us sufficient information power because our study had a relatively narrow specific aim, the study was exploratory, we recruited from a population that was unique to our research question, and we had a professional moderator with experience fostering meaningful dialogue.

Participants were directly recruited from local areas that have been historically marginalized and in which a large percentage of the population is from racial and ethnic minority groups by posting fliers at community-based pediatric health centers and local community-serving nonprofit organizations. Study information was also posted to a listserv of one of these community organizations. For participant convenience, the focus groups were held at sites within these communities. Three were held at community centers in an area of Washington, DC, where over 90% of the population is Black and over 20% of the families are living in poverty. A fourth was held in Spanish in a multicultural learning center catering to the Latine population with limited income in an area of Washington, DC where over 25% of the population is Hispanic/Latine.[22] We also held a fifth focus group of key informants who were local leaders from agencies serving these historically disinvested communities, several of whom were members of these communities. The data gathered from the key informants was used to help enhance the understanding of the themes developed by the community focus groups.

Each focus group was led by a professional facilitator with experience leading focus groups in this community. The sessions were audio recorded and professionally transcribed. The Spanish focus group was professionally translated and checked for accuracy by the facilitator. Notes were taken at each focus group to augment the transcription.

Participants received a meal during the focus groups, childcare as needed, and a $25 grocery store gift card at completion. At the start of each focus group, participants completed an anonymous demographic questionnaire and provided informed consent.

Focus Group Moderator Guide

The moderators guide was developed by C.L. with help from an experienced qualitative researcher with expertise in medical education and an experienced qualitative researcher with expertise in community engagement. The guide was informed by prior studies that sought community input about academic medical centers and trainee curricula,[8,16] and was pilot tested with a community focus group (incorporating feedback through minor modifications). The guide included questions about the perceived health of participants' communities; how social determinants of health, including racism, have affected them and their community; and what they would want a physician to learn in a curriculum focused on health equity during their training (provided as online supplementary data).

Data Analysis

We used an inductive approach to content analysis[23] to identify the key themes from the focus group data. All authors (M.B., P.B., C.L.) independently reviewed one transcript line by line to create codes and then met to compare and come to a consensus on the codes to be included in a codebook. The codebook was reviewed and agreed upon by all 3 authors. The remaining 4 transcripts were coded by 2 authors independently (P.B., C.L.) who then met to review codes and update the codebook as needed. Any discrepancies were discussed with the third author (M.B.) to achieve consensus. After coding

completion, all authors met to create categories which were used to determine themes.

Reflexivity and Trustworthiness

Transcripts were coded by investigators with diverse racial and professional backgrounds and expertise in various topics relevant to this study. M.B. manages community initiatives for our institution, a role which immerses her in health promotion programs within the community of study. P.B. is an inpatient clinician with experience in qualitative research and medical education who has an interest in social drivers of health. C.L. provided primary care for 18 years within this community and is an experienced medical educator. This diversity of perspective allowed for the exploration of multiple ways of interpreting the data, which was discussed in regular team meetings during both the coding and theme development. Any disagreement among the team was discussed until consensus was reached. Journaling was performed by the principal investigator, C.L., to reflect on the data collection and process of analysis. Themes were cross-checked with data obtained from the key informant focus groups. Findings were supported with rich description using verbatim comments.

This study was approved by the institutional review board at Children's National Hospital.

Results

Participants consisted of 65 community members who took part in 1 of 4, 90-minute focus groups. Seventy-four percent (48 of 65) self-identified as Black/African American and 25% (16 of 65) as Hispanic/Latine (TABLE). The key informant focus group had 10 participants representing various community-based organizations ranging from schools to local political leaders to nonprofits servicing families of children with special needs.

Overall, the 4 community-member focus group (FG) participants described 6 core themes, which were echoed by the key informant focus group (KIFG). These themes identify important components for inclusion in a health equity curriculum from the community's perspective.

A Healthy Community Is a Community With Access

Participants described a variety of resources to which they needed access to remain healthy. They talked about safe outdoor spaces such as "a park for exercise, no trash in the parks" (FG3) and playgrounds for kids. Participants also identified access to nutritious foods as another factor for keeping their community healthy. As one participant noted, "All we got access to in our communities is Chinese food, liquor stores, and single cigarettes. That's all we got access to, so that's why our health is so—you know what I mean?" (FG 2) Without access to places to purchase nutritious foods and safe places for physical activity, community members felt it would be hard to maintain health.

Participants also recognized neighborhood infrastructure as an element of healthy communities. They described the importance of access to a good education through quality schools in their neighborhood. They also elucidated how access to reliable transportation and a clean environment helps to maintain health.

TABLE
Focus Group Participant Demographics[a]

Demographic Category	n (%)
Age (N=63)	
18-25	6 (9.5)
26-34	18 (28.6)
35-54	30 (47.6)
55-64	5 (7.9)
65+	3 (4.8)
No answer	1 (1.6)
Children <18 in household (N=62)	
Yes	49 (79.0)
No	13 (21.0)
Race (N=65)	
White	5 (7.7)
Black or African American	48 (73.8)
American Indian or Alaskan Native	0 (0.0)
Asian or Asian American	0 (0.0)
Native Hawaiian or Pacific Islander	0 (0.0)
Other	11 (16.9)
N/A	1 (1.5)
Hispanic/Latino (N=62)	
Yes	16 (25.8)
No	46 (74.2)
Highest education (N=56)	
Some high school	12 (21.4)
High school graduate/GED	24 (42.9)
Some college	12 (21.4)
Associate degree	2 (3.6)
Bachelor or higher	6 (10.7)
Other	3 (5.4)

[a] Although no income data was collected, based on self-report of neighborhood of residence, 2/3 of participants (39 of 65) came from areas of Washington, DC, where more than 20% of families live in poverty.

System-Inflicted Stress Weighs Heavily on Health

Participants described in detail the stresses that they face in everyday life, which range from concrete concerns like how to pay the bills and how to make sure that their children are well cared for to more systemic threats such as racism and prejudice. They detailed how all-consuming these types of stresses can be when you don't have support or a backup system. All the pressure from exposure to these stresses takes a toll on both their physical and mental health. As one participant put it:

> *… our brothers is out there being held down thinking that the only thing that they can do to survive is hustle and sell on the streets because nobody don't want to hire them because they've been incarcerated, because they've got a track record this long, because cops is out there pinpointing. All of that affects our mental, our physical … It affects our physical because if you're stressed … our blood pressure raises. … Then our body starts to break down. That's when disease starts to form. (FG 1)*

They also discussed how environmental exposures that arise from systemic inequities can be an underlying cause of disease. They identified factors such as violence, smoke, drugs, and poor housing conditions as triggers for health problems.

Communities Have Internal Strengths

Participants highlighted the intrinsic resources of the community, including initiative, ownership, resilience, and community bonds, as strengths. Participants prided themselves for being hardworking with a strong sense of self and identity, having close support networks, and cultivating the ability to advocate for themselves individually and collectively. They spoke of the history of these strengths "We're resilient. We came over on ships." (FG 1) They also expounded on their willingness to keep moving forward even if it means trying new things.

The following quote from a key informant illustrates other strengths raised by participants:

> *They have a strong sense of self, a strong sense of who they are, and maybe the narrative that's often spoken about them, they don't always subscribe to that. They are kind of like, well, maybe that's the way you view us, and maybe that's the way you would describe us. But if you were to come and kick it with me over in Anacostia, you would see something possibly very different and have a very different experience. And I think there is something very empowering about self-definition, even though everybody else would be like "oh those are just, you know, the Black and Brown poor people over there who won't amount to much of anything," and they're like, "No. I see myself and my future, the prospects for my children, very differently." (KIFG)*

Racism Affects Care Delivery

Participants felt that interactions with the medical system were clouded by stereotyping and mistrust. As one participant stated: "We don't want to be stereotyped all the time. We don't want to be judged, and we don't want people always assuming that all of us act the same … " (FG 4) Participants felt like they were being condescended to and not being treated as well as others based on their skin color: "They talk to us like we're different, like we don't understand." (FG2) Participants also explained that many interactions with the medical field left them feeling like they were being judged negatively and therefore being undertreated. They felt that stereotyping and racism led physicians to focus on things that were not necessarily relevant to why they were seeking care. As shared by one participant:

> *I went to a doctor for a lump, like a little small lump or a cyst in my arm. … I left out of there. I had kidney problems. I left there with potassium pills, high blood pressure pills, and the doctor didn't even take time to refer me out to another doctor or to get like testing done or a biopsy or anything. She just looked at the number, statistics that in your age range, African American females had diabetes and high blood pressure. (FG 4)*

These sentiments were compounded by the historical context of systemic racism in the community.

> *Slave mentality and the vestiges of slavery and Jim Crow and what that does to the thinking, to not feeling as though communities deserve to be healthy, you know. (KIFG)*

Respectful Bedside Manner Is Necessary to Build Trust and Better Health Outcomes

Participants spoke about the importance of respectful interpersonal communication between them and their clinician as an enabler of better health outcomes. They wanted their physician to "just be open-minded and listen, like they say. Be transparent." (FG2) Feeling like they were being treated with respect and being kept abreast of their own health was particularly important. Participants expressed a strong desire to be heard by and connected to their clinicians, endorsing a bedside manner that was free of judgment, bias, and condescension.

For example, my primary care doctor right now is a doctor that I feel gives me attention, gives attention to all I say, my complaints, my pains. … He asks a lot of questions, he looks at me in the eyes, he sits in front of me, and asks if I want to speak in English or Spanish, however you prefer. That is the part where I feel comfortable, I feel like he is paying attention to what I'm saying. (FG 3)

Experience the Community to Learn and Appreciate Strengths and Needs

Focus group participants believed it was critical for clinicians and those in training to know the community, and become familiar with the neighborhood characteristics, the historical perspective of the community, available resources, and the risk factors they face. One suggested strategy was to have the health care professional pair up with a community member to visit recreation centers, daycares, churches, schools, parks, local stores, and thereby develop a better understanding about the struggles and opportunities experienced by the community they serve. Other strategies included performing home visits and attending community meetings and town halls to get to know the community (see BOX for exemplar quotes).

BOX Exemplar Quotes From Theme 6: Experience the Community to Learn and Appreciate Strengths and Needs

"I would take them to grocery stores and to the convenience, the local convenience stores as well as the pharmacies, so that when they assume they we can get certain products over the counter or they assume that certain things should be a part of our diet, the assumption is removed because they'll get to see with their own eyes what we do and do not have access to, and therefore, sometimes—because sometimes I've encountered doctors who don't want to write a prescription because they feel like you can go and get it locally, and then it's an inconvenience to you. And you believe them, and you go in there, and it's not there." (Focus Group 1)

"Like if they came into the community and all that stuff, they don't know about certain communities and stuff. They can have an advocate with them, someone out the neighborhood to get to know about certain things about the neighborhood. Like a person that do know what's going on, like they have in certain housing and communities, they have a resident XXX thing, and those people that sign up for them things, like it's a president and a treasurer and all that stuff. They know about their community because they've been living there a long time." (Focus Group 4)

"From day one of medical school or whatever … some aspect of cultural competency and health inequities to be in their curriculum and not just the first year but like throughout, including residency … that there is some cultural competency training that is ongoing … to graduate or whatever it is to advance, you have to have experiences in different communities … if you're going to the medical field and you know that you don't know who is going to walk through your door, you don't know their racial, ethnic, or cultural background, that you should be having some kind of cultural competency training from the moment you are welcomed to that medical school." (Key Informant Group)

Discussion

Our exploration of the community perspective in planning a health equity curriculum illuminated 6 core themes related to contributors to and protectors against health disparities as well as what residents should learn about them. Although some of our findings have previously been described in the literature, the community often had a nuanced perspective that would not otherwise have been identified. These nuances exemplify why it is important to query the community when developing a curriculum aimed at improving their health.

For example, the importance of access is one theme that has been described in the literature, but the community's viewpoint was slightly different than what is typically described. Traditionally, health access has referred to the ease of obtaining medical care,[24] but more recent literature on addressing disparities has called for focusing more broadly[25,26] just as community members in our study suggested. Our participants valued factors like access to transportation and a good education. In other words, they highlighted the importance of the social drivers of health. These are defined as "the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."[27] Therefore, curricula around health disparities need to focus more on teaching residents about how resources are allocated[28] and emphasize frameworks such as structural competency[29,30] that allow learners to appreciate the importance of social drivers in health outcomes.

One of the most talked about social drivers of health during the focus groups was racism. Community participants discussed not only how the stress of living under systems of oppression directly affects their health, but also how racism in historical context leads to long-standing mistrust of the medical profession which also effects health outcomes. Even though systemic racism was not as commonly discussed in public when these focus groups took place in 2019, the community members clearly understood the important role that it played in their health. Since that time, there has been extensive reporting on the evidence of the effects of racism on health[31-33] and multiple calls to action to address the long-term consequences of systemic racism.[28,34,35] In fact, the American Board of Pediatrics now suggests that pediatricians should be

able to identify populations placed at risk for poor health outcomes by acknowledging "that a history of medical experimentation, abuse, and exploitation of marginalized populations directly contributes to the mistrust these populations have toward the medical profession."[35] The results of this study provide yet another argument for the historical lens that must be covered in any health disparities curriculum.

Another component of addressing health disparities that community members stressed was good communication skills. Communication skills have long been recognized as an important part of residency training; the ACGME has identified Interpersonal and Communication Skills as a core competency since 2001. These skills are not usually associated with health disparities training, despite research showing correlation between good communications skills and better health outcomes,[36] and that racial and ethnic minorities and populations from lower socioeconomic statuses experience poor quality patient-clinician communication.[36] Since studies have shown that resident communication skills can be improved through training,[37] an important component of any curriculum that aims to address health disparities should integrate communication skills training with a focus on communicating with diverse populations.

Community members brought additional suggestions less described in the literature as related to health disparities education. For example, participants emphasized the importance of understanding the intrinsic resources within communities that are traditionally considered underresourced. They talked about the strength of community bonds that exist as well as the resilience and strong sense of identity of community members. This is supported by the groundbreaking work on community assets: Building Communities From the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets.[38] Yet, despite finding several examples of asset-based curricula for residents[39-41] and calls for clinicians to spend more time in the community learning directly from local residents about their lives,[8] to our knowledge, few residency curricula emphasize the strengths of the community members.[7]

Our study has several limitations. The data was collected in 2019, but due to shifting priorities and clinical responsibilities during the COVID-19 pandemic, the data analysis was significantly delayed. Although there has been a national reckoning with the history of systemic racism in this country since the focus groups took place, the community we worked with was well aware of systemic oppression even if it was not acknowledged by the general public at that time. Because we sought to deeply explore perspectives in a single city, our themes, though generally well supported by the literature, may have limited transferability to other cities. Participants in this study were primarily recruited through email or social media making the voices of those without access to computers less likely to be heard. Additionally, we purposely sampled from areas of Washington, DC, with predominantly Black and Latine populations and therefore may have missed the perspectives of other subgroups experiencing health disparities.

Despite these limitations, our findings are consistent with the recommendations of several recent publications that delineate topics to be covered in curricula aimed at reducing health dispartities.[28,35,42] Many of those topics, such as the importance of good communication skills and understanding the historical underpinnings and structural drivers of inequities, are found both in these recommendations as well as in the words of our focus group participants. Other areas, such as the importance of getting outside the hospital walls and really delving into the strengths of the community members themselves, are not as universally recommended yet are deemed important components of a health disparities curriculum in this study further demonstrating the importance of the community perspective.

Next steps include integrating the themes that we heard from the community with our literature review and resident needs assessment to create relevant learning objectives and appropriate teaching experiences. By working with community partners, we hope to develop meaningful experiences for our residents while keeping voices from the community part of the curriculum. Just as in CBPR, having the community voice in curriculum development will help shape a resident experience that is more responsive to community needs and will improve the likelihood of helping eliminate disparities.

Conclusions

To our knowledge, this is the first study to query the community perspective on building a curriculum about health disparities. The themes identified by participants reinforce what is already expressed in the literature while highlighting new concepts to include in a health disparities curriculum.

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Funding: This research was funded in part by a George Washington University School of Medicine and Health Sciences Medical Education Grant.

Conflict of interest: The authors declare they have no competing interests.

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Received May 25, 2023; revisions received August 16, 2023, and September 27, 2023; accepted October 4, 2023.