Research Topics

Communicating for social justice in health contexts: Creating opportunities for inclusivity among marginalized groups

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Communicating for social justice in health contexts: Creating opportunities for inclusivity among marginalized groups

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Editorial: Communicating for social justice in health contexts: Creating opportunities for inclusivity among marginalized groups

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Editorial on the Research Topic
Communicating for social justice in health contexts: Creating opportunities for inclusivity among marginalized groups

The articles in the Research Topic *Communicating for social justice in health contexts: Creating opportunities for inclusivity among marginalized groups* attend to the foundational premise of health equity, social justice, identity, and advocacy. They are global in their scope, spanning contexts ranging from rural voices in Chaquizhca, Ecuador, to reproductive justice and abortion, pain literacy, health practices in low-income Malays, community participatory approaches to Chagas prevention in Guara, Ecuador, and stigma and marginalization faced by children with disabilities in Europe and Central Asia. The inequities addressed by the papers in this issue interrogate racial, structural, socio-environmental, and ethnic disparities.

The Research Topic was conceived and completed before the COVID-19 pandemic, which profoundly shaped our ways of thinking about the deeply intertwined relationship between health, health communication, inclusivity, representation, and social justice. As we move into the post-acute crisis phase of the COVID-19 pandemic, the continued urgency of their impact and relevance highlights how these disparities serve to increasingly perpetuate the systemic differences in the access to behavioral, preventive, and treatment opportunities by disadvantaged and vulnerable populations. The articles in the Research Topic, thus, present a rigorous examination of the structures that perpetuate the inequities in healthcare outcomes and the higher morbidity and mortality burden faced by vulnerable populations and utilize approaches ranging from a critical cultural critique of the rhetorical construction and cultural consumption of women's pain to community-based participatory research and culture-centered approaches.

Recent scholarship has examined how the COVID-19 pandemic highlighted the interconnections between health communication, social determinants of health (SDoH), health inequities, and public policies. Ataguba and Ataguba (2020), for instance, draw our attention to the importance of effective health crisis and risk communication in building trust, credibility, honesty, transparency, and accountability. We have come to acknowledge the need for empowering marginalized populations (Dutta, 2018), for centering an equity-focused global health agenda (Jensen et al., 2021), for recognizing the significance of culturally sensitive communication with diverse audiences, and for being mindful of community values, preferences, and relationships. These facets are especially significant given the disproportionate burden of morbidity and mortality on people from vulnerable populations (Bhaskar et al., 2020).

Bates et al. interrogate the multiple meanings of health and wellbeing through a critical cultural analysis of a project called the "Healthy Living Initiative" set in Chaquizhca, Ecuador. The authors argue for centering community voices in understanding what health means, identifying issues that are defined as health concerns by members of the community, and designing the solutions through a dialogic approach drawing upon the meanings and practices emphasized by community members. Taking a culture-centered approach (CCA; Dutta, 2008), the authors destabilize the positionality of an expert in understanding health, privileging in its place the positionality of the community voices, and engaging the community in an act of creation to understand health. The definitions that emerge from their study emphasize the role of community, of local knowledge, and of collective advocacy in driving meaningful change.

In her article on reproductive justice advocacy at an abortion fund, Gantt-Shafer conducts an ethnographic examination exploring how the organizers of an abortion fund use new media to create community outreach about abortion. Now more than ever, Gantt-Shafer's study draws out the tension between community empowerment, confrontation of systemic oppression, and societal silence around stigma with the role of new media in spreading and cultivating misinformation, (mis)representation, and misogyny. Her study highlights the challenges faced by those working to advocate in a stigmatized domain in building solidarity and how their employment of community building and movement organizing helps sustain transformative narratives, create solidarity, and support organizations in material and symbolic ways.

In her paper, Huse employs community-based participatory research (CBPR) to examine how a partnership between scholars and community members from marginalized populations can cultivate relational empowerment by incorporating social identity in its research design. Critiquing the tenets of the CBPR approach, Huse deftly reviews its applications and strengths to understand how social identity theory can be used to guide communication interventions more effectively among the multiple stakeholders and team members that comprise CBPR research teams. Her paper furthers the CBPR paradigm in significant ways by aligning concerns of marginalized community identities with social justice in achieving meaningful change.

Hawkins' paper employs CCA to focus on the disproportionate HIV burden faced by the Black gay, bisexual, and other men who have sex with men (BMSM) community. It critiques the Center for Disease Control and Prevention's (CDC) Testing Makes Us Stronger health communication campaign that targets the BMSM community without authentically capturing the experiences of its target audience and thus perpetuates the very systemic inequities that the campaign seeks to address. His study emphasizes the need for community involvement in designing health campaigns and suggests ways that CCA can help integrate community-based understandings of culture, systems, and agency in the context of HIV care for the BMSM population.

Taylor and Glowacki undertake a critical cultural examination of the rhetorical construction and cultural consumption of women's pain, exploring pain literacy from the perspective of pain expression and perception. Examining mediated examples that exemplify how women's pain is mystified and perpetuates a system that contributes to a lack of agency for women in pain, their study has implications for women's health, particularly in the diagnosis and treatment of conditions where expressions of pain may be misunderstood or miscontextualized. Their holistic view of pain literacy and what they term "rhetorical care" has implications for women's agency, and the cultural and racial competencies that shape diverse interpretations of pain articulation.

Kaur-Gill et al. report on a CCA-based health intervention with low-income Malay Singaporean community members. Emphasizing SDoH, they argue for centering the voices of the community members to understand their meanings of heart health. As their paper highlights, meaningful ownership that cultivates agency and empowerment of community members through active involvement can help counter the "hegemonic production of heart disease" (p. 14) through privileging local voices and appropriating agency in the presentation of illness from biomedical experts. They advocate replacing biomedical language with simple and clear, jargon-free communication to address persistent health disparities in this domain.

The potential of meaningful cooperation between community members, national stakeholders, and researchers was highlighted in Bates et al.'s paper critiquing how community voices exemplified in the co-participatory design of a song are strengthened through adoption by national stakeholders. In their second paper in this issue, Bates et al. focus on Chagas disease prevention in a youth-based program set in Guara, Loja Province, Ecuador. Chagas is a tropical condition that disproportionately targets marginalized rural communities.

Employing entertainment education lens to promote behaviors for preventing Chagas, the authors identify the opportunities and challenges of working with national stakeholders in addressing the factors that contribute to perpetuation of the disease.

Peinado et al.'s review of HIV communication and health disparities outlines how minority and marginalized populations are disproportionately impacted by HIV-related disparities. Their literature review identifies approaches and suggests avenues for communicating effectively. Their review emphasizes the significance of health communication in addressing stigma and bringing about behavior change that reduces HIV-related disparities. As the authors note, such studies are especially relevant in addressing persistent disparities that have complex and interrelated causes spanning intersecting individual, social, contextual, and environmental tensions.

Stevens et al. focus on the stigma and discrimination faced by children who have been diagnosed with some form of disability. Using the social ecological model, the researchers highlight the importance of contextualizing the treatment of children with disabilities to include professionals, non-professionals, and community members, and by addressing systemic discrimination through multilevel approaches. Their study has implications for guiding national policy and legislation that protects the rights of children with disabilities.

The World Health Organization (WHO, 2004) has emphasized the need to center communication, messaging, and health communication channels in addressing uncertainty and managing misinformation, among other factors, to design a successful response to health emergencies. As we collectively emerge in a post-COVID-19 crisis pandemic era, the range of health communication perspectives taken by the researchers in this issue, spanning CCA, CBPR, and EE, among others suggest a fertile and productive avenue for taking on the multiple and intersecting health challenges that highlight the interconnected global yet intimately local nature of health and its meanings. The relevance of social media, patient education, and the multiple platforms where conversations about health occur has evolved in unexpected ways to challenge how our assumptions of health access, interventions, advocacy, and multi-sectoral structural change operate. Taken together, the articles in this Research Topic underscore the urgent need to focus on health, health outcomes, and communication in the context of marginalized and vulnerable populations in critical and innovative ways through foregrounding their intersections with advocacy, voice, identity, and social justice.

Author contributions

The author confirms being the sole contributor of this work and has approved it for publication.

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

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Painting a Community-Based Definition of Health: A Culture-Centered Approach to Listening to Rural Voice in Chaquizhca, Ecuador

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The terms "health" and "well-being" are commonly used in health communication research. These terms, despite calls for a consensus definition, are rarely explicitly defined. We argue that, instead of imposing a universal definition of health or well-being, communities can be better served if we adopt a culture-centered approach (CCA) and listen to their local, contextualized definitions of health. To demonstrate community articulation of a definition of health, we offer an analysis of wall art created by and with a community and our service and research team. After understanding a definition offered by a rural community in Chaquizhca, Ecuador, we articulate how a community-based definition of health can become a culture-centered way to operationalize definitions offered by the World Health Organization in ways that better serve local communities.

Keywords: definition of health, Ecuador (country), asset based community development, service-learning (SL), children

INTRODUCTION

"Health" is a key term in health communication, yet there is very little agreement on what "health" is. Although there is widespread agreement that the World Health Organization definition, first articulated in World Health Organization (1948), that health is a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity," this conceptualization defers us to another term: "well-being." Indeed, in their respective reviews, Niebroj (2006), Webster (2009), Huberts et al. (2011), and Brussow (2003) each found that the terms "health" and "well-being" are used in multiple competing ways by multiple health and communication researchers. Instead of a shared definition, these reviews found that communication scholars diverged from each other and from medical scholars, and that the findings from one study could not be directly translated to other studies because they did not share explicitly fundamental definitions of their phenomena.

Webster (2009) claims that a unified definition of health and of well-being is needed to "allow for communication across disciplines and the ability of researchers to build upon prior studies" (p. 25). More forcefully, Niebroj (2006) asserts that, without a unified definition, patients, doctors, and societies will abuse the power of medicine and commit malpractice. Others (e.g., Habersack and Luschin, 2013) believe that the failure to have a clear definition makes national law and policy to support health difficult.

It may be useful to remember however, as Bircher (2005) does, that "since antiquity the ways in which the word "health" has been used were closely related to the thinking at the time" (p. 338). That is, although there is an allure to a constant and consistent definition of health, what "health" means changes across times, spaces, and contexts. Bircher's view reminds us that most decontextualized definitions of health are written by actors in the global North. As such, these definitions have been developed in contexts that emphasize the role of a rational choice-making individual (Dutta-Bergman and Doyle, 2001; Dutta-Bergman, 2005a), removed from the social, economic, and environmental contexts in which that individual resides (Dutta-Bergman, 2004a,b), and (re)produce systems of health that exert "expert" control over bodies at both the interpersonal (Dutta-Bergman, 2004b) and mass media levels (Dutta-Bergman, 2005b).

To better address the actual health desires of a people, and to avoid setting health agendas in ways that advantage dominant regimes, Dutta (2008) suggests that, rather than assuming experts from the global North understand what health is, a culture-centered approach (CCA) that uses a dialogic approach is better able to allow members' voices to become the "starting points for understanding what health is, what the health problems faced by the community are, and the ways in which such health problems might be dealt with" (p. 107). Fundamentally, this alternative approach requires, at least, "locating the agency for examining health practices," defining problems to be addressed, and suggestions "in the culture being studied," rather than in the expert, and "emphasizing the meanings that are co-constructed by the researcher and the cultural participants" (Dutta-Bergman, 2004a, p. 259).

This argument for local communities to define health is similar to the one offered by Zoller (2012) when she accesses activists' definitions of health: that "definitions of health, like all definitions, are political and service particular interests" (p. 22). If we accept a definition without first understanding how that definition emerges, we may unwittingly (or worse, wittingly) support particular theories of the causes of disease and ill health, who is responsible for those causes, and what the appropriate response to disease and ill health is. Zoller (2010, 2012) outlines three primary approaches to understanding health in contemporary public health. First, biomedical approaches (e.g., germ theories, genetic theories, bio-psycho-social theories) emphasize the role of microorganisms and mechanical breakage in the body and promote classical bureaucratic capitalist responses. Second, lifestyle approaches look to individual choices and personal agency in health outcomes, thus leading to neoliberal responses. Third, structural approaches argue that access to or lack of access to social, economic and political resources needed for health leads to health outcomes, thereby calling for radical interventions. Although these are primary approaches to defining health in the global North, Zoller makes clear that these approaches can intersect, there are lacunae among them, and there are other definitions that they likely omit. To understand how a community thinks about health, and thereby gain insight into its theories of illness causation, responsibility, and treatment, we must engage that community specifically. That is, rather than imposing one of these approaches to health on a community, we should instead consider how, within cultural and socioeconomic contexts, the material and symbolic elements of health are brought together by specific communities (Zoller, 2005).

To move away from purporting to offer *the* definition of health and to give voice to *a* definition of health, and to illustrate the utility of Bircher's and Zoller's approaches to multiple, contextually bound definitions of health, we offer a discussion of a community definition of health articulated in Chaquizhca, Ecuador. We argue that by listening to the voices in that community articulating their own definition of health, we are able to avoid imposing an academic/governmental definition on the community. This act provides opportunities for engaging the community to assert agency in developing its health and well-being. We begin by outlining in greater detail the assumptions of the Culture Centered Approach. We then turn to the community of Chaquizhca and how we engaged with that community. After providing a description of our processes at a school to allow a community definition of health to emerge, we discuss how that definition was displayed—literally, on a wall—in the community. Finally, we offer some implications this analysis could have for approaching communities in defining health for themselves as well as some ways that our engagement with the community informed the larger project called the "Healthy Living Initiative."

THE CULTURE CENTERED APPROACH TO HEALTH COMMUNICATION

Across multiple cultural contexts, the CCA has demonstrated both its ethical and practical power in addressing health issues in a way that empowers marginalized populations and de-centers expert control over societies (for an overview, Dutta, 2018). Communication, in the CCA, emerges from and exists at the intersections between and among three powerful concepts: culture, structure, and agency (Dutta, 2008). In their White Paper, Dutta et al. (2016), see also Dutta (2018) outlined these three concepts. They write, "culture reflects the shared values, practices, and meanings that are negotiated in communities," "structure refers to the systems of organizing that enable or constrain access to resources," and agency "depicts the enactment of everyday choices and decisions by community members, amid structural constraints that reflect the daily negotiations of structures" (Dutta et al., 2016, p. 4). To access and understand communication that emerges from these intersections, Dutta et al. assert that "the core methodological tool for the CCA is dialogue" (p. 5). Although dialogue is the core tool, this dialogue is encountered with specific techniques including ethnographic observation, focus groups, interviews, community forums, photovoice, and other practices in which dialogue between researchers and community and between community members and other members can be enacted.

The utility of the CCA is well-recognized, and analyses that focus on each of these concepts helps to interpret how local communities negotiate issues of health and well-being in ways that resist assumptions imposed by the global North. Moreover, whereas the standard approach often imposes an understanding of health on a community, the CCA can access and make clear local marginalized communities' constructions of health. While the CCA places agency at the theoretical core, Dutta and Basu (2007) recognize that culture "emerges as the strongest determinant of the context of life that shapes knowledge creation, sharing of meanings, and behavior changes" (p. 561). In applications of the CCA, across multiple contexts, the role that culture plays in shaping possibilities for health communication is evident. The ways that culture guides and is guided by understandings of health is well-documented in cases of understanding general health among Bangladeshi immigrants to the United States (Dutta and Raihan, 2013) and among African Americans (Dutta et al., 2018a), as well as specific health contexts such as coronary heart disease among medically underserved South Asian immigrants to the US (Kandula et al., 2012), diabetes among Zuni First Nations members (Newman et al., 2014), family planning among young women in Nepal (Basnyat and Dutta, 2011), and dietary choices by Asian Indians living in the US (Koenig et al., 2012). These findings regarding culture are not, however, claims that culture itself is a barrier to change (as is often assumed in the standard approach), but rather that culture helps articulate shared knowledges of what constitutes health and healthy behaviors, as well as providing guidance on what calls for behavioral change would be consonant with and what is dissonant with other lived practices in communities.

Each of the issues encountered in studies that emphasize the role of culture also encounter a variety of structures. These include economic structures that limit access and affordability, as well as gender, filial, and other structures that guide and are guided by behavior. Although the aforementioned studies also discuss these structures, other analyses emphasize structure in explaining so-called health choices. For example, Dutta et al. (2018b) argue that foreign domestic workers in Singapore face structural employment conditions that block both access to health care and deny domestic workers the rights of citizens to articulate their need for this access. Although Dutta et al., found that foreign domestic workers and their employers had similar cultural understandings of what health is, the economic structures that allowed exploitative employment and the legal structures that prevented domestic workers from challenging this abuse had powerful impacts on health that standard approaches to health communication would be unlikely to identify. In this case, structure limits the agency of the domestic workers to challenge their conditions (see also Gao et al., 2016; Dutta and Kaur-Gill, 2018, for how narratives of mobility and agency are contradicted by Singaporean and US society for Bangladeshi and Chinese migrant workers, respectively).

Finally, agency emerges between culture and structure. Agency does not mean that people are able simply speak and act as they wish, but agency in the CCA is constrained and enabled simultaneously by the cultures in which one resides and the structures that exist. Each of the aforementioned studies also indicates how agency is shaped by and shaping of both culture and structure. This agency, often expressed in dialogue among community members and between and among community members and activists, workers, and scholars of change, emerges most clearly in sympathetic environments that are cultivated specifically to allow participation (e.g., Dutta, 2014, but for a specific application of a photovoice project addressing hunger, see Dutta et al., 2013). However, agency also emerges in environments that are less sympathetic to dialogue such as traditional Entertainment Education consultancy approaches (see the debate among Dutta and Basnyat, 2008a,b; Linn, 2008). When opportunities for participation and dialogue are present, community-based definitions of health and approaches to reach health are more likely to emerge, but if, and only if, participation and dialogue are employed for true listening and not as a fig leaf to hide a global northern actor's pre-determined definitions and implementation programs (Dutta, 2014). Our mural project, executed in the community of Chaquizhca, sought to enact this kind of dialogue.

THE PROCESS OF COMMUNITY ENGAGEMENT

The mural project on the school wall was developed as part of a multi-year service-learning collaboration between Ohio University's Infectious and Tropical Disease Institute (ITDI), Pontificia Universidad Católica del Ecuador's Center for Health Research in Latin America (CISeAL), and their partner communities in Loja, Ecuador. The service-learning program functioned within a larger participatory research intervention designed in conjunction with our Healthy Living Initiative (HLI), a long-term, multidisciplinary research initiative that aims to support sustainable socioeconomic development of rural communities as the main tool for the control of Chagas disease (see, for example, Grijalva et al., 2015; Nieto-Sanchez et al., 2015; Marco-Crespo et al., 2018; Oduro et al., 2018; Patterson et al., 2018).

Collectively, ITDI, CISeAL, and the communities work toward bringing health services to traditionally marginalized communities in Ecuador. Although the larger project addresses these services in multiple communities, the focus of this paper is on an engagement with Chaquizhca, a small community in Chile Parish, Calvas County, Loja Province. The fifty (50) houses in this community are located in a dry mountain subtropical forest ecological zone, reflecting a yearly annual rainfall between 1,600 and 3,200 mm, an average relative humidity of 78%, and an extended rainy season from December to April (Campozano et al., 2016). The terrain is mountainous and marked by deep dendritic ridges. Home locations are one to two km above sea level, dispersed, and often difficult to access because of poor road conditions and limited transportation options. Most of the members of the community practice subsistence agriculture or perform day labor; their socioeconomic conditions are affected by limited job opportunities, poor access to sanitary, health and education services, and isolation and marginalization that restrict their access, participation, and competitiveness in larger markets.

Chaquizhca has one school. It is named after the date it was founded, "*Escuela de Educación Básica 27 de Octubre*" (Basic Education School, 27th of October). Each day, the school serves 20 to 35 children; daily attendance varies depending on planting and harvesting seasons, weather, and other factors. The students range from 5 to 12 years of age, which corresponds to first grade (equivalent to US kindergarten) to seventh grade in the Ecuadorian system. The school is staffed by three teachers, one each to deliver academic content to students in first grade, to students in second to fourth grade, and to students in fifth to seventh grade. It is composed of two larger classrooms (one for second to fourth grade, combined, and one for fifth to seventh grade combined) and one smaller classroom (for first grade). It also has a kitchen area and sanitary facilities. In the front of the school, there is a cemented multipurpose play area with two soccer goals and two basketball hoops at its ends, and two poles in the middle for installation of a volleyball net.

During this project (implemented in the summers of 2013, 2014, and 2015), the service-learning team conducted assets-based interviews, asset-mapping activities, and focus groups with community members in three communities in Loja province, including Chaquizhca (all activities were approved by the Institutional Review Board at Ohio University and/or the Comité de Ética de la Investigación en Seres Humanos at Pontificia Universidad Católica del Ecuador and are reported in, among others, Marco-Crespo et al., 2018; Oduro et al., 2018; Patterson et al., 2018; Bates et al., 2019).

Our work employed Kretzmann and McKnight's (1993) model for Asset Based Community Development (ABCD) and sought to identify community interests and strengths. This model emphasizes a community's assets rather than needs as a point of departure for community revitalization. For example, cultivating and connecting already-present knowledge of the location of medicinal plants, traditional culinary combinations of agricultural crops to create complete proteins, or being able to make porotillo brush brooms that spread a natural insecticide (Nieto-Sanchez et al., 2015) may better serve the community than asking why the community lacks a pharmacy, does not buy meat at a supermarket, or does not often spray highly toxic commercial pesticides. By cultivating these practices and connecting non-practicing members of the community to practicing members, ABCD approaches seek to provide opportunities for community members to invest their gifts, skills, and abilities and, by becoming more aware of individual and collective assets, communities will be able to create more opportunities to share, collaborate and invest their assets. The expectation is that communities will then become healthier, thriving spaces and be better equipped to meet future challenges. In a service-learning collaboration, focusing on community assets rather than needs allows service projects to be led by community interests, as opposed to perceived deficiencies (Jacoby, 2015). This emphasis on community strengths contributes to an environment of collaboration, and potentially deconstructs the standard approach's assumption that "the helper or, in this case, knowledge-based development agency, has the 'answers' and disseminates them ex cathedra to the doers" in development projects (Ellerman, 2001, p. ii), and as such, challenges the paradigm that is problematic in many service-learning partnerships (Jacoby and Associates, 2003).

The ABCD approach, like the CCA, upends critical assumptions in the standard approach (Mathie and Puntenney, 2009; McKnight and Russell, 2018). First, the ABCD approach challenges the assumption that communities are in a knowledge or resource deficit and, instead, asserts that communities are rich in assets and have significant knowledge of their lived conditions. Second, the ABCD approach rejects the idea that outside agencies should see themselves as empowering local communities to change and, instead, insists that communities begin by addressing their own concerns and decide collectively whether outside agencies should be involved in efforts for community change. Third, the ABCD approach does not evaluate success on whether the goals of a grant proposal or a millennium development indicator goal have been attained but, instead, views enhancing collective community visioning and community relationships so that they determine their own goals and resources as the primary outcome of interest.

Rather than bringing pre-determined definitions of problems, and their accompanying solutions, as is done in the standard approach, enactments of ABCD approaches are guided by five themes (Ellerman, 2001; see also Hirschman, 1973; Kohr, 1973; Schumacher, 1973). First, the community that is engaged must be encountered where it is and through its understandings, and not seen as a blank slate to be written on by outside influences. Second, actions must be guided by the knowledge, values, and worldview of the community, not those of the outside influence. Third, transformative change should not be a form of social engineering to impose neoliberal structures and values on a community. Fourth, "benevolent" charity should not be employed as it degrades the receiving community and creates dependencies on international aid organizations and global northern nation-states. Fifth, and finally, the community must be the leading agent in social transformation. This approach, then, with its acknowledgment of issues of structure, power, voice, and agency in social change, and its call to resist the standard approach, fits well with the CCA.

The community maps generated through the asset-mapping process provided us insight into the communities' perceived resources and assets and the composite asset maps provided the communities with data and a visual representation of local agricultural resources, interests and skills of community members and infrastructural assets in the communities (Bates et al., 2019). This asset-mapping process led to the development of a community gardening initiative, which informed subsequent service-learning projects including this school mural project. In addition to assembling play equipment in the schoolyard, the teachers and principal at the school serving Chaquizhca expressed interest in having the newly reinforced wall painted as a collaborative service-learning project. They informed the service-learning team that they wanted to use the wall to depict healthy living. After the Institutional Review Board at Ohio University determined that the wall painting was exempt from review as non-generalizable, non-systematic investigation of publicly observable behavior, they approved an oral community-based informed consent procedure. Before the children began their work on the wall, informed oral consent from all parents and schoolteachers was obtained, and oral assent from the children was obtained. After consent and assent was affirmed, the children guided what should be painted on the wall.

Specifically, over a 15 day period, we engaged the children of the community in a series of dialogue, discussion and drawing exercises (see Nazir et al., 2013 for a sample process guide). On the first day, the children split into pairs and together listed all the words that came to mind when "culture," "community," and "healthy living" were used. All of the children's' ideas were recorded on a white board. Over the next 3 days (days 2, 3, and 4), the children used markers, color pencils, and crayons to draw their answers to three questions: "What would you like to see in your community in the future?" (day 2); "How can you preserve your culture in the future? How can you practice your culture?" (day 3); and, "What can you do to make your home/family/school/community healthy?" (day 4). On the fifth day, the children and teachers were asked to determine what they thought the most important ideas were, and the children focused on the theme of a healthy life and chose specific ideas that they thought were the most important to a healthy life (described below). Following the weekend (days 6 and 7), on days 8 through 12, for an hour each day, the children self-divided into three groups: one groups of painters, one group of actors, and one group that wanted to neither paint nor act. The process followed by the actors will be discussed elsewhere. Children who neither wanted to paint nor act helped in the community garden or worked on homework. The painters used these 5 days to create a rough sketch of their ideas on paper, draw these ideas on the wall at larger scale, and to paint to fill in those drawings. The project team, after the children returned to class each day performed minor touch up and applied varnish to the paintings to protect them from the elements. After the next weekend (days 13 and 14), on day 15, the children who chose to paint presented the finished wall (and the children who chose to act presented their play) to the community. Over 100 people attended the event, including family members, community members from Chaquizhca, project staff, and teachers and children from one of the neighboring communities. This wall displays the definition of health articulated in Chaquizhca.

READING THE WALLS TO DEFINE HEALTH

After the children and teachers were asked to generate a listing of the features that were needed to have a child grow up healthy and happy, the list was reduced by asking children and teachers which messages they wanted to memorialize on the new wall around the school. Each wall segment became a panel to be decorated. Each segment of the wall is about one meter tall at each end, declines in a wedge shape to the middle third of the segment and flattens such that the wall is approximately half a meter tall. The segment then inclines in a matching wedge until it is again one meter in height and flattens. Each panel is ∼10 cm thick and three meters in length. Each section face is painted white, with the top painted in alternating red, yellow, and blue: the colors of the Ecuadorian flag. Although nearly 20 panels would be available, there would not be enough space to memorialize all of the potential contributions. The teachers and children decided that they wanted images of healthy lifestyles, to display the rights of children, and to recount a well-known folktale from a volume illustrated by the children at the school. Put formally, the teachers insisted on the inclusion of two panels promoting social health, the children preferred nine panels promoting physical health, and the remaining panels, the children and teachers agreed, would promote ethical health of children through storytelling.

SOCIAL HEALTH

Although the two teachers clearly held positions of authority over the children, they only insisted that two panels be devoted to the issue that the teachers thought most important: social health of the child. In so doing, the teachers enacted their structural authority over the children to include what they believed to be an important message. Although the teachers did not use the term "social health," they insisted that institutions—institutions that guide the political, educational, and social structures of rural Ecuador—recognize the voice of all citizens, no matter their status. They also held that the formal recognition of rights is a strong path toward recognizing this status. Their framing, then, fits well with the World Bank framing of social health (see, Davis, 2004; United Nations, 2016). Specifically, these two panels refer to the Convention on the Rights of the Child adopted by the United Nations General Assembly in 1989 and ratified by Ecuador in 1990.

The first panel (see **Figure 1**) simply states, "*Derechos del niño/a. Los niños tenemos derecho a:*" (Rights of the boy/girl. The children have the right to… " Here, there is explicit reference to the treaty on the rights of the child. To ensure that all children are included, the ratified language is slightly altered. Rather than referring to the rights of the "*niño*," literally boy, the teachers asked that the language allow both boys (*niños*, also translatable as children) and girls (*niñas*) to be named on the wall. Although this is a minor change textually, the use of inclusive language may be important for promoting gender equality in the community. The words are painted in the colors of the Ecuadorian flag: yellow, blue and red. Each group of three letters repeats this color order, thus tying the rights of the child to an explicit manifestation of Ecuadorian identity. In including both boys and girls as having these rights, this panel may also authorize both boys and girls to have agency and voice in their community.

The second panel, using the same color scheme, explains what these rights are (see **Figure 2**). The final line of panel one serves as an introductory clause. Here, in naming the specific rights, we see that the rights exceed those contained in the Convention on Human Rights. In accordance with the Convention, the wall states that children have the right to life (*la vida*) and to a family (*tener una familia*). Although the Convention explicitly names a right to life, the having of a family may be broad enough to incorporate the Convention's demand that the child be included in a familial grouping, even when their biological parents may be unavailable. Similarly, the Convention's requirement that children be protected from exploitation and

FIGURE 1 | *Derechos del Niño/a*.

FIGURE 2 | Rights of the child.

abuse appears to be reflected in the right "*ser respetado y a no ser rechazado*" (to be respected and not rejected). Other terms from the Convention, however, are not included on the wall, such as the Convention's assertions that no child may be enslaved or suffer capital punishment. Just because the teachers and the children did not include these, however, does not mean that they would accede to slavery or to the death penalty. Instead, the children expanded the list of rights. We see that the children engaged in a dialogue to include other rights not contained in the Convention. The children also claimed the right to health (*la salud*), to play (*jugar*), and to education (*la educacion*). There is some slippage, perhaps intentional, between the rights that are demanded from a human rights perspective and those that are demanded by members of the community. In any case, the listing of rights, colored with the hues of the Ecuadorian flag, may make these rights present and localized, and, in turn, may make children and parents more aware of the inherent rights of the child for social health. That is, by tying together the resources provided by the world (the Convention) and the nation (the flag), the children and their teachers wove their rights, using an agentic voice, into two already existing powerful structures.

PHYSICAL HEALTH

The second grouping of panels was most strongly informed by the children. For a child to grow up healthy and happy, the children of Chaquizhca thought that children should play "*¡deportes saludables!*" (Healthy Sports!). These nine panels begin with an introductory panel with this phrase (see **Figure 3**). Sports (*deportes*) appears in the center in block letters, while the modifier healthy (*saludables*) is written in red script immediately under it. Both words are framed by exclamation points following Spanish grammar. In the upper left sooner of the panel appears a stylized Ecuadorian flag, while a flag for Calvas county (where the school is located) appears in the upper right corner. The remaining panels illustrate what the children mean by healthy sports.

FIGURE 3 | *¡Deportes Saludables!*

Some of the panels illustrate independent play. For example, one panel (see **Figure 4**) shows four children jumping rope, two boys and two girls. Behind the first boy is a rectangular brown structure. Between him and the first girl are a series of rounded humps, one with an additional upright shape. Between the first girl and second boy is a swing set, and between that boy and the second girl is a slide. Over the shoulder of the second girl is a tree on a hillside. Upon closer examination, it becomes clear that these four children are students at the school, and they are enjoying the new playground that the service-learning team has helped them build. The rectangular structure is the newly extended school house, and the rounded humps and structure are a play set dragon made of used tires by members of the service learning team (see **Figure 5**). The swing set and slide were also installed at the same time the play set dragon was built In a very real sense, the children are using new enabling structures that are now present in their community. In addition, the four children are children from the group that participated in this wall painting exercise. Although members of the service learning team painted all of the children on the wall the same color and shade, the children remixed brown, white, and yellow paint to

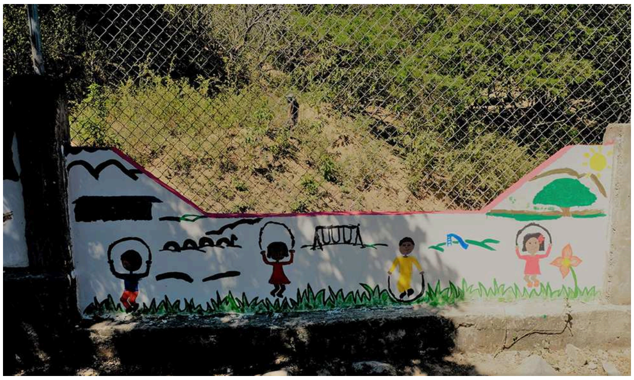

FIGURE 4 | Children jumping rope.

FIGURE 5 | Dragon on the playground.

FIGURE 6 | Additional play.

FIGURE 7 | Children cycling.

achieve colors as close to their own skin tone as possible, and each child painted themselves into the wall. Whenever any child appears in any panel on this wall, it is the self-representation of a specific child at the school, and, in painting themselves into the picture, the children appear to be anacting agency over their own representation. A second panel (see **Figure 6**) shows additional play. Children perform jumping jacks, head stands, sit-up, trampoline jumps, and stretching exercises, each a part of the children's structured physical education curriculum at the school. Here, we see that the structure of the school curriculum comes into play as a means of defining physical health.

The final panel displaying independent play occurs outside the school (see **Figure 7**). In the center is a girl in pink, riding her bicycle down a path. She has just descended a hill along a long windy path. The hill is largely barren, with a brown dirt road weaving between green land devoid of trees. Two other cyclists are descending the path as well. All three children are headed toward a village on a verdant hill. The green is much brighter and more solid. A bright blue river or road weaves down this hillside. The scene is meaningful in multiple ways. Many of the children take similar journeys each day coming to and from school. Although only a kilometer or so separates the schools and homes in a direct line, the rugged hillsides hills require many switchbacks, leading to hours-long journeys each way. The school sits on less productive land, while the homes are on richer land that sometimes has better access to water. The scene drawn by the children reflects, perhaps, more than play. In addition, this panel reflects well how culture shapes the children's understanding of physical health; geography shapes where homes can be placed, and the placement of homes creates the conditions for transportation, and the conditions for transportation then influence how geography itself is navigated. Participating in healthy activities can allow a child the strength to manage this journey each day, and the home structure and geographical structure creates this need for a particular kind of health body.

Other panels depict team and cooperative play. In most panels, as in the cycling and playground panels, the upper left and right corners contain images of the hillside, local homes, or the sky to help situate the panel within Calvas County; the play occurs within a particular set of places and spaces. The only panels that do not appear to be bound within Calvas County are the panels featuring basketball and volleyball. In the basketball picture (see **Figure 8**), three players in green take

FIGURE 8 | Basketball.

FIGURE 9 | Volleyball.

FIGURE 10 | Soccer.

on two players in red. A girl from the green team shoots the bright orange basketball toward the net. In the volleyball picture (see **Figure 9**), three players from the blue team are ready to return the shot from the four-person green team. The action here takes place on a bright yellow volleyball court divided by a red net. All teams are mixed-sex. Whereas, all of the other images could contain makeshift or common equipment, these images show specialized equipment and specialized uniforms. This may explain why they do not show the hillside or the school; because they are specialized sports, they may require special places to be played. These pictures, as manifestations of healthy sports show an idealized version of basketball and of volleyball. Although the school does have a single volleyball and a volleyball net that can be stretched over the unpainted concrete forecourt of the school, the school has no uniforms for a team. And, in contradiction to the image painted, the school has no basketball uniforms. In this case, rather than indicating a resource that is present, the children may be exercising agency to call on the school to use its structural resources to provide this additional equipment.

Standing in opposition to this specialization is an image of children playing soccer (see **Figure 10**). In this image, we see on the left end a hillside topped by the local water pumping station (a station then-recently installed as a community resource to provide water infrastructure to the community). Near the bottom of the hill, a girl in a red shirt and blue plants guards the goal. A boy in a blue shirt and green pants is kicking a brightly colored ball toward the goal as a second girl, this one wearing a red dress, defends. At the other end of the pitch, a boy in a green shirt and blue plants waves that he is open for a pass and a third girl, wearing a red skirt and red shirt, stands ready in case the ball comes her way. The final child, a boy in a red shirt and blue pants, stands where we would expect the goal on the other end to be. A local home appears behind him instead. Here, we see a much less formal setting for team play. Although there appears to be some sense of teams—the red team against the blue team—there are not uniforms; indeed, the final boy stands out, as we cannot be sure to which team he should be assigned. There is also limited equipment; there is only one goal on the pitch, and the ball does not appear to be a regulation ball. Even though they may not have uniforms and equipment, the children appear to be having fun. Their game can be played by anyone, anywhere, and with limited equipment. This sense of openness to play, and the ability to play anywhere, is also reflected in the two remaining panels (not shown here). The children playing marbles and the children at tug-of-war could be playing nearly anywhere and without needing expensive specialized equipment. Collectively, these panels reflect a setting that reflects the children's ability to make-do, and thus enact agency, within a structurally limited environment. They also show how these children can focus more on what is available to them—i.e., a single goal, a ball, a circle drawn in the dirt, a length of rope—and less on what is not available. Although they operate within a set of structures that could be read as limiting their right to play, the children are able to transform their resources into enabling factors.

ETHICAL HEALTH

The final set of panels—eight in all—illustrates a story. This story was narrated by the children to our service learning team, written and illustrated by the children into a small book, transformed into a play enacted by the children, and then painted onto the wall (see **Figure 11** for an example). This story emerged over time in

FIGURE 11 | Fox and Rabbit.

engaging with the children of the community. It is a story of Fox and Rabbit, a significant, multi-part, ongoing narrative shared in Andean communities (see Howard-Malverde, 1981; Allen, 2011 for a review). Fox and Rabbit are important characters in a tale that is well-known in Andean cultures, including this community in Chaquizhca where the children told us the story. In each story, sly Fox attempts to eat the wily Rabbit, and Rabbit generally thwarts his plans. As a story from oral tradition, it has been retold many times, in many ways, and in diverse combinations. The storyteller can weave any one Fox and Rabbit story into other stories, or tell each as a stand-alone story. As such, Fox and Rabbit are cultural resources that can be employed to teach lessons to young people (and anyone else who might be listening).

The children told us a story that they found particularly amusing. In the children's telling, Rabbit is caught in a trap while stealing vegetables from an old woman's garden. Fox promises to let Rabbit out of the trap. Rabbit tricks Fox into staying in the trap, just for a moment. Rabbit, having stuffed himself with vegetables and believing Fox to be trapped, takes a long nap. The old woman sees Fox in the trap and decides to cook him for dinner in retaliation for her belief that Fox has been eating her vegetables. Fox persuades the old woman that, because he is very skinny, he cannot have eaten her vegetables and that he will make a poor stew, but he knows where he can find something good to eat. Fox seizes the sleeping Rabbit, and, together, Fox and the old woman have a rich stew.

Like many stories, this tale of Fox and Rabbit contributes to the ethical health of the children in the community. It draws on a cultural resource to teach children lessons about honesty and hard work that contribute to a healthy, functioning community. What makes this story unusual in the Fox and Rabbit lore is that Fox is the victor in the story. Both Rabbit and Fox are trickster characters. Rabbit, in this incarnation of the story, takes on an unusual role in that he is an unredeemed trickster. Rabbit is to be punished for his thievery, and he attempts to redirect his punishment to Fox. Fox, in most stories, is simply ravenous, and this means that his hunger takes over his decision-making processes. He may have let Rabbit out of the trap in order to eat Rabbit, but he is tricked to get into the trap himself. Although Fox is trapped, he retains enough of his cunning to escape the old woman's stew pot. Fox recaptures Rabbit so that Rabbit can face the consequences of his thievery. Not only is Rabbit justly punished, but also Fox easily caught Rabbit because Rabbit had become complacent. Had Rabbit not been so gluttonous following his vegetarian larceny, and had Rabbit not become slothful, Rabbit may still have had the opportunity to escape. Yet, because Rabbit took a food-saturated nap, Fox caught him. Layered within this story are multiple possible ethical lessons, for example, that punishments await thieves, gluttons, and indolents and that, if one keeps their head in a stressful situation, one can overcome hardship. As indicated by Booth (1988), the stories we tell propose a "way of living" (p. 205); that is, they offer lessons that allow individuals and communities to develop an ethical community. Moreover, when the children of the community retell this story of Fox and Rabbit, they are recirculating these lessons and showing their internalization. It is important to remember that, although ethical development of children is rarely, if ever, mentioned in definitions of health that emerge in the global North, the children specifically chose to include this story and its moral lessons when the articulated their definition.

In addition to offering explicit lessons to children for ethical choice, the sharing of this story offers an additional layer of ethical health. Stories, Booth continues, are invitations to do more than accept a worldview, they are invitations to see a storyteller as a potentially valid and valued interlocutor. As he (1988) puts it, the "act of deciding whether to accept" the gift of a story "is itself a gift" (p. 222). When the children offered this story to our team, they were not merely telling a story, but they were asking us to see them as interlocutors. That is, they sought agency through storytelling. And, when we listened to the story, we accepted the gift of story while offering the gift of our listenership. Through this exchange, this Andean folktale could provide additional insights for how we could engage the community. Stories, like that of Fox and Rabbit can unlock the history, values, and morals of a community; they can articulate culture as a resource. When they are told, stories gain the attention of others and create a community of enjoyment around these topics. When the least powerful members of the community tell the stories, in this case, the stories also allow the emergence of voice and agency. The children in this community not only told us a story they had heard, but hailed us to become listeners to that story.

CONCLUSIONS AND IMPLICATIONS

The children and teachers at this school in Chaquizhca named three components of health that they thought meaningful and worthy of memorialization on the wall surrounding their school. They wanted to promote in their community social health, articulated through the rights of the child, physical health, in the form of healthy sports, and ethical health, as shared in stories of Fox and Rabbit.

These indicators of health reflect, in some ways, common definitions of health, but with variations that make them meaningful to this community. That is, by responding to the culture-centered approach's call for "creating spaces for cultural voices to make articulations about their health needs," the wall mural project allows children in Chaquizhca to redefine "health beyond the narrow biomedical framework to look at cultural resources that enable health" (Dutta, 2017, n.p.). "The children's focus on healthy sport in interpretable, in part, though the WHO definition of health in that it is a reflection of physical well-being. This reflection emerges from the community in two ways. First, and most obviously, the places and modes in which physical health is manifested through play are painted to place these activities in the community. Second, physical well-being in the WHO indicators list is defined by the presence or absence of communicable and non-communicable diseases and mortality rates (World Health Organization, 2015a). The children and teachers, though, articulated their definition through bodily function—i.e., the ability to perform sport—as a clear indicator of physical well-being. This may connect to the largely agricultural and manual labor valued in the community as well as the need to be able to walk long distances and navigate unsteady terrain, labor and physical environments that focus on a body's ability. For this community, then, function may be a better indicator of a person's physical health than weighing the child on a scale or taking their blood pressure would be. Similarly, social well-being is articulated in the rights of the child and, in part, the ethical health through storytelling. This social health can be put into the WHO's language that social health inequities derive from infringements on fairness and human rights norms World Health Organization (2015b). The WHO recommends that addressing social and economic relationships is one way to promote social health; the community's articulation of these relationships through the rights of the child—both those formally recognized in international law and those articulated within the community—may be a means of seeking social health for children in Chaquizhca. Finally, although the WHO defines mental well-being as a condition where a person "can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (World Health Organization, 2002, p. 1), their operationalization of mental well-being is through scoring standard measures of depression, anxiety, substance abuse, and the like (World Health Organization, 1998). The community in Chaquizhca, however, in articulating a narrative of what makes for a productive and fruitful contribution to the community, and what would be harmful, sidesteps these supposed objective measurements and articulates ethical participation in the community in unexpected, culture-centered ways. We articulate these fits with the WHO definition not to indicate that they reinforce the WHO definition. Instead, we articulate them because these connections may expand on and exceed the WHO definition. As Dutta (2014) might put it, since "Working with the language of the structure is also the site for resisting the language of the structure," when we draw the definition offered in Chaquizhca into the WHO definition, "the vocabulary in the mainstream is altered through the participation of other vocabularies" (p. 77). In doing so, these connections enable us to use the WHO language to exploit the resources of the global North and deliver them to communities in the global South, if and only if the communities we work with ask us to help them exploit these resources.

Collectively, then, these articulations reflect, but modify, the WHO definition of health. This rearticulation demonstrates the utility of Bircher's contextually-bound, multiple interpretations of a definition of health. The localized definition allows access to the potential for physical, social, and mental health commensurate with a culture and its location. Because of the cultural and geospatial terrain of Chaquizhca, the articulation of physical well-being as physical function, social well-being as expressed through the rights of the child, and mental and communal well-being as ethical health through storytelling, we attain a definition of health that is both meaningful and actionable within the community but also interpretable and actionable within the vocabulary of the World Health Organization and other external agencies.

In addition to displaying these values, the community-articulated definition of health in Chaquizhca offers an additional value. Because it is developed from the community, rather than imposed by representatives of the global north, the definition created by the children and teachers at this school is better able to offer an assets-based, culture-centered definition of health rather than a deficit-based, universal definition. The WHO measures physical health, despite claims otherwise, as the presence or absence of death and disease; the community articulated their landscape and school as places and structures that demanded and created physical fitness. The WHO measures of mental health look for lack of mental adaptation to stresses; the community articulated their cultural heritage and stories as providing guidance for dealing with challenging situations. Finally, although the WHO looks for disparities in social health, the community articulated their agency within national international legal structures through a claim to rights they possessed and, therefore, the fundamentals for social well-being.

In addition to these implications for defining health to take advantage of WHO and other structures, the definitions offered in this community offer opportunities for practical action. Following Zoller's (2010, 2012) claims that definitions of health also entail assigning responsibility for ill health and programs of action to seek health, the definition offered by the community in Chaquizhca also offers these implications. Of the three models, offered by Zoller, the community's definition is most like the structural approach. The structural approach, however, is one that is premised on a deficit model, and is not fully compatible with the ABCD or the CCA approaches adopted here. The community's emphasis on rights of the child for social health, physical function for physical health, and honesty and hard work for ethical health also entail programs of action. If social health is injured, the children's articulation of responsibility is to the state and other larger organizations for failing to support their rights and, thereby, entail a social and legal solution. Because of this linkage, one member of our larger project team has begun to more deeply explore how rights are understood and articulated in Chaquizhca and neighboring communities to better activate these solutions. When physical health is absent, the children point to a lack of physical function and their images suggest that geographical factors and school factors are the likely cause, entailing solutions that are based in infrastructure. In response, our project team has been asked by the community to connect community members with cantonal and provincial authorities to advocate for greater investment in infrastructure in the communities, such as roads, schools, and water systems. Finally, when ethical health is harmed, the children note failures to learn from cultural knowledge that teaches sound values and this entails leveraging resources like the Fox and Rabbit stories, and others, to restore community values. Given this connection, our project team is assisting the communities in recording and preserving a variety of local knowledges, including stories, medicinal lore, and more. These actions—advocating for rights, seeking infrastructure investment, and recording oral histories—may not be traditional health interventions as understood through the definitions of the global north, but they are health interventions when we adopt the definitions that are offered by the community of Chaquizhca and take them seriously as grounds for action in cooperation with the community.

These definitions allow us to emphasize how the community in Chaquizhca can approach health and development differently than in the standard approach. Rather than emphasizing disparities and deficits, the community emphasizes the assets that support health and development. The schools and teachers enable collective advocacy and change, local knowledge is emphasized, and the landscape is transformed from challenge to opportunity. In adopting a contextually-bound and multiple interpretation of health, the community allows us to better serve them and prevents us from imposing an external definition of health that will always already find the community lacking. We encourage other health and development researchers to similarly listen to the definitions offered by the communities they serve.

DATA AVAILABILITY

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

This study was carried out in accordance with a protocol approved by the Institutional Review Board at Ohio University. The current study was determined exempt from IRB review because it was judged to be non-systematic and non-generalizable intervention. A community consent protocol was used for this study in which parents and school teachers agreed to allow the children to participate.

AUTHOR CONTRIBUTIONS

BB and DM contributed conceptualization and design of the study. CN-S and DM organized and conducted fieldwork related to the study and the larger project. MG coordinated community involvement and participation from local institutions. BB wrote the first draft of the manuscript. DM, CN-S, and MG wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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A Community-Based Heart Health Intervention: Culture-Centered Study of Low-Income Malays and Heart Health Practices

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This paper reports the formative research findings of a culture-centered heart health intervention with Malay community members belonging to low-income households. The community-based culture-centered intervention entailed working in the grassroots with community stakeholders to tailor a heart health campaign with and for low-income Malay Singaporeans. Community stakeholders designed and developed the heart health communicative infrastructures during six focus group sessions detailed in the results. The intervention included building smoking cessation information accessible to the community, the curation of heart healthy Malay centric recipes, and developing culturally responsive information infrastructures to understand a myocardial infarction. The intervention sought to bridge the gap for the community where there is an absence of culturally-centered communicative infrastructures on heart health.

Keywords: cardiovascular disease, health disparities, culture-centered intervention, participatory research, health justice

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INTRODUCTION

Every year, ∼17 million people die from poor heart health conditions (Patel and Preedy, 2016). Globally, heart disease remains the number one cause of death. Coronary heart disease (CHD) has emerged as a critical public health burden across the developed and developing world. The burden of poor heart health is distributed unequally across societies. In Singapore, CHD afflicts minority communities such as Malays and Indians more so than the majority ethnic Chinese population (e.g., Sabanayagam et al., 2009; National Health Survey, 2010). This paper reports a complete culture-centered intervention conducted with low-income Malay community members to address the heart health disparity faced. The results are based on six focus group discussions conducted as part of the formative research that went into developing the culture-centered heart health intervention. The formative research designed the heart health intervention materials for and with Malay community members from low-income households through a culture-centered process.

Building on the medical and public health evidence regarding ethnic disparities and heart disease (e.g., Sabanayagam et al., 2013; Rakun et al., 2019), we argue for heart health can be understood through the lens of racial, economic, and health inequality, by centering the voices of those most afflicted by the heart health burden. The Malay community faces jarring heart health disparities compared to other ethnic populations in the country (Sabanayagam et al., 2009; Kaur, 2018). This research expands on the racial, economic, and health disparities by specifically interrogating heart health meanings through the lens of low-income Malay Singaporeans that are socio-economically disenfranchised.

HEART HEALTH DISPARITIES

CHD often termed as a lifestyle specific heart disease, is a global public health concern. In Asia alone, CHD rates remain on the uprise (e.g., Khor, 2001; Lam, 2015). In lowering risks of CHD, the biomedical literature indicates the need for individuals to partake in risk-reducing behaviors, modifiable through lifestyle changes (Pencina et al., 2019). Modifiable heart healthy behaviors include smoking cessation, reduction of alcohol intake, diet, exercise, and the tackling of obesity (Sturgiss and Agostino, 2018). However, Kaur (2018) argues that for structurally disadvantaged communities, the lowering of risks is beyond lifestyle centered decisions. The inability to negotiate or access health structures are embedded in everyday disparities faced by disenfranchised communities. A critical challenge remains for communities unable to participate in modifiable heart healthy behaviors. These limitations include the knowledge of good heart healthy practices and access to biomedical infrastructures when requiring diagnosis and treatment (Kaur, 2018). Yet, the realities of heart health include communities that live with the disparity remain unable to navigate the complex heart health etiologies concerning the management of heart-healthy behaviors. In theorizing the relationship between health inequalities and economic inequalities, Farmer (2003) interrogates the limits to achieving the substantive opportunity to health access as the vicious effects of economic disenfranchisement that have material and social consequences, implicating an individual's ability to receive better health outcomes. Barriers to what may seem as lifestyle choices limit opportunity for communities to acquire good heart health practices or access modifiable heart healthy behaviors. The biomedical literature continues to grapple with risk factors that go beyond the traditional interpretations of risk. A recent study revealed the role of financial stress in the incidence of CHD among the African American population (Moran et al., 2019), while other studies have identified psychiatric conditions impacting extent (Allan et al., 2019; Hamieh et al., 2019), including stress from situations such as prolonged armed conflict (Jawad et al., 2019).

More recent studies are providing insight on heart health that move beyond the dominant readings of heart healthy behaviors as modifiable risk factors. Marmot and Allen's (2014) discussion on the social determinants of health equity indicates priorities toward the social determinants approach to smoking, obesity, and alcohol consumption. The social determinants approach reveals how individualizing health as lifestyle centered, fails to pay attention to external factors that drive poor health behaviors (Marmot and Allen, 2014). For example, Koh et al. (2010) share how often social determinants are an interaction of factors that heighten health disparities such as the geography, the population dynamics, risk factors, and nature of diseases faced. According to Koh et al. (2010), this approach helps to reframe how public health stakeholders recognize how conditions of inequity inform why socially disadvantaged groups face more significant disparities in health. The social determinants approach focuses on social and environmental factors as fundamental toward achieving more significant health equity among economically disenfranchised communities. For example, Chaudhry et al. (2011) study on racial disparities of heart health among Black populations in the United States located literacy on heart health as contributing to heart health disparities. Health illiteracy refers to the inability to acquire "a constellation of skills, including the ability to perform basic reading… tasks required to function in the health care environment" (p. 123). Disenfranchised Black populations in the United States were unable to negotiate the health care environment with limited literacy on heart health dysfunctions (Chaudhry et al., 2011). The health care environment operating from a biomedical framework is often a confluence of complex negotiations that create barriers for disenfranchised communities to access health systems.

In the Singapore context, a study by Kaur (2018) with low-income Malays found that they were often disadvantaged by lower levels of literacy, were digitally disconnected, impeding their ability to seek health information on heart health. This led to further disparities in heart health literacy. They were often unable to acquire information on the signs and symptoms of myocardial infarction (heart attack) or a stroke. Cameron's (2013) study with South Asians in the United States also indicated the role of health literacy that impacted heart health information seeking among the community. Cameron (2013) parlayed the role of communication messages toward improving equity in heart health through culturally responsive messages in health interventions. In assessing heart health literacy, cultural, and structural factors should be accounted for in understanding disruptions in managing good heart health practices.

In narrowing down the social determinants approach, Dutta (2016) conceptualizes the structural determinants of health approach to studying health inequalities. Dutta (2016) suggests that health experts pay attention to macro-structural factors as opposed to individualized responses to health inequalities when researching health inequalities. A similar critique is posed on how communication, public health, and, medical education literature often sells persuasion messages toward good heart health practices that remain based on individual lifestyle changes, such as persuading individuals to change their diets, to stop smoking, and to get more physically active (e.g., Schooler et al., 1998; Rimal et al., 1999; Mollen et al., 2013). Dutta (2007) critiques individual health promotion messages as limited in their capacity to achieve targeted heart health outcomes. Messages on healthy eating, smoking cessation, and exercise fail to capture the broader structural parameters that limit opportunities for economic disenfranchised communities from making heart health changes, where the "powerful advertising machinery of the sugary sweet drink industry, availability of spaces to exercise, opportunities for leisure amid work in multiple shifts to simply afford a living, and the role of stressors in the broader neighborhood environment on the desire to exercise (p. 2–3)" remain challenging for economically disenfranchised communities.

This study adopts a culture-centered approach (CCA) to design a heart health intervention to work through the health disparities in the context of disenfranchisement, moving away from the critiques of traditional methods to health promotion. We employ the theoretical and methodological tenets of the CCA in developing a community fronted intervention. Our research questions interrogate how heart health meanings are negotiated in the everyday lived experience of living in a low-income context? How do various structural forces influence and impact low-income Malay Singaporeans experiences of heart health?

THE LOW-INCOME CONTEXT

Operationalizing, who constitutes the low-income in Singapore, remains challenging with no official measure of poverty in the country (Tan, 2016). Academics studying the low-income context in Singapore have suggested a few indicators as critical measurements of families living in poverty (Glendinning et al., 2018). An estimate of 20–35% of households in Singapore resides in relative poverty within a population of 5.8 million (Donaldson et al., 2013; Smith et al., 2015). Relative poverty is conceptualized as taking into account "the standard of living in a society as well as social exclusion" (p. xi). Within this percentage, 110–140,000 approximate households are argued to reside in the absolute poverty spectrum, which means that basic needs remain challenging to meet for these households.

There is much debate on the existence of absolute poverty in Singapore with some scholarship using the Average Household Expenditure on Basic Needs (AHEBN) as a data point. According to Donaldson et al. (2013) report on poverty in Singapore, the AHEBN consists of "the average expenditure on food, clothing, and shelter in a reference poor household living in a one to two-room Housing and Development Board (HDB) or government rental flat, multiplied by a factor of 1.25 to account for other household needs like transport, education, and other necessary expenditures for normal living" (p. 60). Donaldson et al. (2013) study reported that based on parliamentary proceedings in 2012 that $1,250 household income per month was a potential indicator of absolute poverty in Singapore. The approximation would be fewer than 140,000 households were living within this range. The profile of individuals within this spectrum included the working poor, unemployed poor, and needy retirees (Donaldson et al., 2013).

Looking more specifically at the Malay community, there was a growing number of Malays that made up the demographic for one and two-room rental flats [1](Heng, 2016; Yayasan, 2016). The income eligibility criteria for rental flats were at SGD,1,500, acting as a potential indicator of living in either relative or absolute poverty. In Donaldson et al. (2013) report, relative poverty is most commonly calculated a 50% of the median household income and the should be within the income bracket of SGD 2,500. None of our participants in the study were within the relative poverty guide if we use the 50% of median household income measurement, as they lived in rental flats where qualification for living in a rental flat was SGD 1,500 and below. Kaur (2018) summarizes that poverty remains "an ideological barrier that has been socially engineered by the state in the framing of the national narrative" (p. 104), disrupting the possibility of rendering a thorough, immersive, and in-depth understanding of the challenges living in a low-income context (Tan et al., 2017; Teo, 2019).

MALAY DISENFRACHISMENT AND HEALTH DISPARITIES

Malays in Singapore face multiple disparities. The literature indicates that the Malay population in Singapore face health, economic, and educational disparities (Mutalib, 2012; Chua et al., 2019; Rakun et al., 2019). In terms of education, housing, and socioeconomic status (SES), there are still critical gaps faced by the Malay community compared to the rest of the population (Mathew and Lim, 2019). Mathew and Lim (2019) elucidate that because Malays make up a significant number of residents in rental flats, a lack of homeownership remained another financial set back for the community in terms of asset consolidation. Heng (2016) reported that in 2016, there were double the number of Malay residents in rental flats in just over a decade from 4.9% in 2005 to 10.9% in 2015. These disparities act as barriers for the community to achieve health equity.

The medical literature indicates that both Malays and Indians in Singapore suffer from CHD disparities. Liu et al. (2016) study reported that Malays and Indians in Singapore suffered from diabetes mellitus, mortality from CHD, acute myocardial infarction, and end-stage renal failure more than the majority Chinese population in Singapore. Liu et al. (2016) caution the excessive risk of native Asians with type 2 diabetes (in reference to the ethnic Malay community) have to CVD. According to Liu et al. (2016), "the excess CVD risk in the Malay group may be attributable to the high prevalence of diabetic kidney disease" (p. 336). The disparity faced is further backed up by a population research report by Yayasan (2016), Singapore's Malay self-help organization indicating that Malays had the highest prevalence of cholesterol, obesity, and hypertension when compared to other ethnic groups in Singapore. Amenable mortality rates were highest among the Malays. Life expectancy gaps among the Malay community compared to the other two ethnic groups were also reflected (Lim et al., 2013).

Furthermore, the rates of smoking were most significant (both male and female) within the ethnic group. Exercise behaviors remained limited compared to other ethnic groups as well (Yayasan, 2016). Furthermore, research on the community itself found that Malay males and females had higher body mass index, reflected more elevated rates of smoking, more significant readings of systolic blood pressure, and hypertension (Mak et al., 2003; Morrow and Barraclough, 2003; Liu et al., 2016). Based on the ontological frameworks of biomedicine, all of these risks would be deemed potentially modifiable.

To further breakdown these disparities, Sabanayagam et al. (2009) interrogated the role of unemployment, educational qualification, and body fat ratio (overweight) to its relationship with diabetes mellitus and hypertension. Sabanayagam et al. (2009) found that socioeconomic status (SES) was related to a

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[1] Rental flats refer to the Public Rental Scheme of retrieving heavily subsidized housing by the state (Housing).

high body mass index (overweight/obese) among Malays, with women bearing a more substantial burden of the risk when they had lower SES. Obesity and poverty share a complicated relationship in the developed world where poverty could mean living with a higher risk of obesity (Alavi Hojjat and Hojjat, 2017). Studying the developed context of poverty and obesity, Alavi Hojjat and Hojjat (2017) position the argument that "obesity is truly a form of serious malnutrition" (p. 20). Healthier diets are harder to access among communities belonging to low SES households SES, face literacy challenges, and are more likely to be a minority community (Henderson, 2007). Challenges remain in the Singapore context as the discourse on poverty in the city-state are couched in ways that erase the experiences of those residing in impoverishment (Tan, 2016; Tan et al., 2017).

THEORETICAL INSIGHT: CULTURE-CENTERED APPROACH TO DISPARITIES

The CCA adopts a critical perspective toward understanding structural disadvantages in its assessment of health disparities. Dutta (2008) informs that the structural determinants of health are built based on a free market ideology where health becomes a commodity to be purchased. "As a private commodity, health has to be purchased, with the rhetoric of personal choice, and individual responsibility inundating the neoliberal propaganda" (p. 2), where the management of health is individualized. Therefore, when studying disenfranchised populations facing health disparities, a structural reading is necessary. Starting from recognizing how low SES communities residing in health systems that operate on a neoliberal logic of health provision often are unable to access health institutions. In not being able to access health institutions, low-income patients may delay treatment or fail to comply with medication prescriptions for fear of health costs (Low et al., 2017; Suen and Thang, 2018).

Individuals from more impoverished communities are also left further disenfranchised when faced with chronic diseases. The poor in Singapore were more likely to suffer the chronic disease burden with a higher prevalence of deficient treatment and management of chronic disease (Wee et al., 2013, 2017). Access to health services remain limitedly used among low-income Singaporeans. A study by Wee et al. (2019) indicated that Singaporeans living in the country's public rental flat scheme for low-income Singaporeans had higher rates of healthcare utilization (emergency room visits and hospitalization). Yet, access and utilization of health resources such as informational services and interpersonal interaction with community health providers remain problematic for the low-income (Wee et al., 2013).

A central aspect of the CCA is configuring grounded up strategies on a community's structural challenges of health before solutioning to reduce disparities. By centering the relationship between culture, structure, and agency, an intervention is designed with community members (drawing from community agency) to address their lived experiences with heart health disparities. The culture of communities forms the guidelines, norms, understandings, frameworks, and membership cues. With local etiologies centered, culturally relevant and structurally accessible materials are developed.

THE CULTURE CENTERED APPROACH TO PARTICIPATORY RESEARCH

In determining heart health interventions, the centering of a community's interpretation of heart health forms a starting point for building academic-community partnerships. Wallerstein and Duran (2010) interpret CPBR as a potential bridge that facilitates community praxis and social action, with science to achieve health equity. Knowledge hybridity that incorporates egalitarian practices of power-sharing, information dissemination, and the production of health resources by experts and community members is central to the CBPR process. The goal of CPBR, according to Wallerstein and Duran (2010), is in creating space for "translational intervention and implementation sciences to influence practices and policies for eliminating disparities" (p. 44). Hacker (2013) describes the goal of CPBR as "creating an effective translational process that will increase bidirectional connections between academics and the communities they study" (p. 2). Note here that the notion of equitability is grounded in academic power over the definitional terrains.

Several heart health interventions using CBPR found that empowering participants through participation in the research process produced culturally relevant and contextually focused health solutions (Taylor et al., 2005; Andrews et al., 2012). The Jackson Heart Study sought to address heart health disparities faced by the Black population in three Mississippi counties. The praxis focus of the CBPR process is in its promotion of equitability in getting all stakeholders involved in the research process and ensuring the centering of voice in deducing research goals, outputs, and outcomes (Taylor et al., 2005). CBPR as a research technique embeds involvement by community members as a fundamental principle of the approach (Hacker, 2013).

Culture-Centered Intervention

The CCA foregrounds the ownership of health infrastructures for participation in the hands of the margins (Dutta, 2008; Dutta et al., 2019). Community members are central in formalizing the key conceptualizations of intervention before the introduction of experts. Experts are fundamentally only present if community members articulate their need for facilitation. Community members remain the primary arbiters in facilitating, designing, and negotiating the intervention proposed. While this research began with a grant by the Singapore Heart Foundation awarded to the researchers for specifically the study heart health in the Malay community. The researchers located natural community organizers through the formative research process that assisted in connecting key stakeholders as primary facilitators of the culture-centered process. The intervention was fully developed by only community members that belonged to the low-income context. Local articulations of knowledge are central throughout the building of the intervention. Recognizing communities at the margins as generators of knowledge turns ownership as the basis for the academic-community relationship, with communities at the margins taking charge of owning the research process, outcome, and output. The culture-centered process thus foregrounds structural transformation as the basis for transfiguring existing power relationships (Dutta, 2008).

Adopting this approach includes thinking about how knowledge is created and shared with communities' local articulations, shifting the power dynamics from the academic partner to the community. The consolidation of power in the academe is shifted, where communities are at the center of the knowledge production process. The promise of a culture-centered intervention lies in envisioning a social justice approach to health by interrogating the very knowledge structures that form the basis for the development of health interventions, with the design and implementation moving beyond empowerment to transforming relationships of power that enable designing and implementing for health equity (Dutta, 2011).

With this understanding of heart health disparities as reflective of everyday inequalities, we begin by asking the meanings of heart health of the Malay community in Singapore. In the culture-centered intervention depicted in this manuscript, we sought to locate localized articulations of heart health meanings, which in turn formed the basis for the community designing a community negotiated intervention that pays attention to the limitations faced in achieving equitable heart health.

Method

A CCA intervention involves the organizing of community members in the solutioning process. This experience can be unique, depending on how community members identify the norms and guides of inclusion and exclusion. In culture-centered interventions, these norms and guides are rewritten based on the infrastructures of subaltern voice. We recruited 15 low-income Malays for six focus group sessions to design and implement health promotion material on heart health in the Malay community. For this specific project located within low-income spaces of Malay communities, the notions of heart health remain complexified amidst the negotiations of community norms.

As researchers, our imaginations of low-income Malay community spaces existed to only capture specific ethnically centered community members within our initial research design. Yet, the low-income Malay community members who participated in our initial dialogues rendered these spaces open and invitational, always inviting members living within the rental flat vicinity to join in the discussions and activities. During the launch event, members from the low-income neighborhoods from all races could participate and learn from the heart health materials developed as specified by community members on the project. Tenets of the CCA locate the rules and norms of participation to be set by those in the margins (Dutta, 2011). These rules and norms articulated by our initial Malay advisory group members envisioned participants in the advisory boards as friends and neighbors that were not ethnically Malay. Community members were invitational for other low-income neighbors to learn about their heart health, thus creating a dialogic space that is open-ended, inviting others from the margins. In sum, using CCA meant that even in participatory design, expert control is removed, transforming what it means to develop an intervention constituted amidst centering community agency.

Context of Recruitment

In approaching the community-centered research study among low-income Malay families, we first needed to identify participants that shared membership norms within a rental flat neighborhood that had strong social networks within specific estates. The formative part of the study included both purposive and convenience sampling of low-income Malay households to understand their meanings of heart health, including reaching out to low-income Malay families by knocking on rental flat doors or through connections with locality-based Malay committee members in the area. In the process, we met with an informal community leader who knew all the Malay residents living in the rental flats and terms of recruitment were directed and organized through the community organizer. With her assistance, we were able to organize six focus group sessions with 12–15 participants for each session. For this research paper, we analyze the focus group findings.

The entire study was reviewed and approved by the Institutional Review Board (IRB) at the National University of Singapore (approval certificate 2484). As community members typically drive culture-centered interventions, we had to go back and forth with IRB for each phase of the project to ensure that the IRB was updated. Due to vulnerability issues, IRB states that all identifiers, such as names or any other details, must be anonymized. Written consent for the collaterals designed were taken from participants featured in them.

All the focus group participants identified themselves as belonging to the community of place (residential estate), residing with each other among three rental flat blocks located next to each other. This meant that many participants were neighbors and friends. Participants ranged from the ages of 25–70 with higher attendance by females than male counterparts. On average, each focus group consisted of 7–9 females and 3–4 male participants. Participants were also generally belonging to the middle to older age groups, with most of them aged 45 and above. The focus group sessions ran for 75 to 150 min each and were conducted under the rental flat blocks known as void decks. At the void deck, there are typically grassroots or NGO organizations that have an office or space for communities to use. We were able to get in touch with a local NGO that provided a space for the focus group discussions. Participants just needed to take lift down from their blocks to get to the center, enabling greater participation and attendance. Even though we did not specifically target participants that had a prior heart health episode such as a heart attack, high blood pressure, high cholesterol, or diabetes, all except two of our participants had heart health-related health conditions.

Data Collection and Analysis

Upon forming the focus group, we ran a total of six focus group sessions with open-ended questions on meanings of heart health, lived experiences with heart health, challenges faced, and heart health knowledge and current resources. These open-ended questions allowed the community members to begin

TABLE 1 | Coding Process.

Codes	Themes
• Absent signs and symptoms (heart attack, stroke) • The Smoking Conundrum (relationship to the body, effects, heart, lung, blocking, dysfunction, stress, need, cessation, rights)	**Heart health meanings**
• Malay diet as identity (Malay dishes, description of ingredients, unhealthy choices, healthy choices, Malay flavor, Malay taste)	**Malay is food**
• Where and when to exercise? (kind of physical activity, space, place, time)	**Heart health knowledge infrastructures**
• My community networks (family, friends, neighbors, identity, relationships) • Information Channels in Everyday life (radio, letterbox, community networks, mobile phone)	**Culturally responsive Heart health**

building the intervention. From there, participants articulated during the focus group session both the challenges to achieving good heart health as well as contributed to the solutioning of culturally-centered material. The focus group data went through a constant process of iteration and reiteration during the coding process with the researcher working with community members on coding the data. All findings were discussed and analyzed with community members throughout the sessions. We worked toward familiarizing ourselves with the initial dataset (first and second focus group data) and coded them (Vaismoradi et al., 2013). The coded dataset was then brought back to the community to discuss before deciding on how the intervention will be designed. The coded set informed our themes. In **Table 1** below, we summarize how the codes generated the themes in our findings.

Breaking Down Heart Health Meanings

The first theme addresses how the community broke down their understandings of heart health. When facilitators asked the participants about heart health, some participants were unable to detail what heart health meant in their meaning formations. What are your challenges with heart health was a salient starting point of the first focus group discussion, where we were met with responses such as "*tak paham terus*" which directly translates to "don't understand at all." Other meanings also emerged such as referring to heart health to "*jantung berlubang* (heart murmur)." The absence of an ontological category for meaning-making can be understood as the lack of ability to make sense of information about CHD or related practices of good heart health from the biomedical literature. This lack of ability to make sense of the traditional definitions of heart health was salient among the majority of the participants. The confusion with other forms of cardiovascular illnesses that were not lifestyle-related was also limiting the understandings of heart healthy practices such as references to heart murmurs in their definitions of heart health.

There was a limited reference to a single conceptualization of the heart health aligned with the biomedical readings of CHD. Instead, the meanings of heart health included the absence or limited knowledge of heart health related material. There were also specific individual interpretations of heart health understandings. A few participants pointed out that poor heart health was often linked to other heart health dysfunctions that were non-modifiable such as a heart murmur. The sharing also entailed heart health understandings that did not fit into the dominant categories of CHD, such as linking it with "having a hole in the heart." When we probed further, participants were referring to the biomedical term known as the ventricular septal defect. Participants described poor heart health descriptions as "like lung, blocking smoking like this can cause *jantung* (heart) not to function" or "stress." While others mentioned its relationship with "high cholesterol can also get stroke." What these understandings told us is how heart disease was also shaped by behaviors. However, they did not interpret these behaviors as lifestyle choices but conditions of dysfunction and stress. These understandings were valuable in terms of assessing the different ways in which participants reflected their interpretations of risk factors vs. how the biomedical frameworks impose the language of lifestyle risk factors as amplifying CHD. When asked if participants have had a heart health episode such as a heart attack, Hashim one of the participants related,

> "I don't know whether heart attack, but I go to doctor, my private doctor check me, ask me to take all the medicine, and then straight go to hospital, and then the hospital stay there for four months. I stop smoking... every morning I take two medicine... one small one big... an inhaler twice a day... that's it"

When we probed further, Hashim was at a loss in breaking down this information further. He was unable to explain to us in detail the heart attack episode, but he knew that he was diagnosed with a heart issue.

Among other participants, the articulations of heart health often engaged meaningfully with specific symptoms. For instance, high blood pressure often emerged as an anchor for community discussions. When the facilitator asked the participants if they had *"tekanan darah tinggi"* known as high blood pressure, a majority of participants exclaimed a resounding "yes."

A participant begins sharing her experience living with high cholesterol. Farah, shares that she was diagnosed with extremely high cholesterol,

> "I got very high cholesterol, 100 mg I have to take... yes (in reference to making changes)... like lettuce..vege... no oily food... change... I go for my blood test... next week let's see what happens".

Farah had wanted to address how to deal with her cholesterol levels in a more in-depth and culturally situated way. The focus group discussion also included asking participants if they thought heart health was a problem for the community, there was a collective response that reflected a resounding yes with a participant adding "of course la have." All participants recognized that poor heart health was a problem in the community and the issue required attention. Heart health was discussed from several perspectives. These included its relationship to diabetes, high blood pressure, cholesterol, and asthma. Stress too was highlighted as part of the heart health conundrum.

Last but not least, smoking was also discussed especially concerning "causing a blockage in the lungs" by participants. Hashim shares "poor heart health because the lung *tak* (can't) function, blocking... smoking... all these... lung cannot function." At this juncture, participants acknowledged that the first step to a heart health intervention meant the building of knowledge infrastructures for the community to understand what heart health issues were, and how to maintain a heart healthy lifestyle while residing as a low-income Malay member in Singapore. In coding their responses relating to knowledge infrastructures, the participants discussed what they thought were the reasons for the poor heart health situation among the community. There was a discussion about the attitudes of the community toward heart health, where a participant shares,

> "because you never take care, you never eat the proper food, you know you got this heart problem, you follow what the doctor advise, just maintain your food, maybe can lower...."

While other participants query,

> eat chillies eh, smoking, oily food. Over high smoking la", "*mesti ada minyak (consumption of overly oily food)". Makan makan, then tidur....malas la... exercise....biase kan* (eating and then sleeping... not exercising)".

Here the participants converse suggesting that the food they eat is typically overly oily, and the lack of exercise are also factors that contribute to poor heart health. While others reiterated "*tak paham (don't know).*" These insights emerged when the facilitator asked what were the attitudes toward heart health in the community?

There was also a discussion on the "money situation" as a fundamental barrier toward diagnosing poor heart health symptoms. On the topic of money, a participant says, "sure if I have money, I will buy good good thing for myself (in reference to purchasing heart healthy foods)... all about money...". The lack of financial assets informed the limitations of heart healthy choices. Money was also directly related to, therefore, as shared by a participant as being "*takut pergi doktor* (scared of seeing a doctor)" as it would involve having cash in hand which many members struggled with having financial assets. The low-income plight is often decision-making amid limited resources culminating into poor outcomes (Tan et al., 2017; Teo, 2019).

Smoking Conundrum

Participants also identified smoking as a critical challenge for poor heart health in the community. In the first focus group, it was quickly identified that smoking was a barrier toward achieving heart healthy practices. Participants understood that tobacco, in general, was bad for health, not just heart health. In further interrogating this question on understanding the repercussions of smoking for the heart, led to further inquiry on why smoking cessation was challenging. Sharifah began the conversation by suggesting that a barrier to good heart health "is that my husband is a heavy smoker." In revisiting this question on smoking, a lot of contention also emerged in the room. As many participants did not want to discuss smoking when this topic re-emerged again in the focus group discussion, there was a dispute. Sharifah, the same participant that identified smoking as a barrier later, suggested that no one in the focus group smoked. Yet, two participants were later recorded as smokers. The interlocutor interpreted Sharifah's retraction as a potential denial amid other participant voices.

When the conversation on smoking was discussed again in the focus groups, participants then said that "they don't think that there are many who smoke" referring to community perception of smoking behaviors. Other participants emerged in the discussion suggesting that "it doesn't make a difference, some people who smoke also get heart diseases" with another participant adding that "my husband smokes, but the one who got a heart attack is me and I don't smoke." A participant also added that it was, in fact, the act of smoking cessation as the point in which one falls ill. Indri shares,

> "if you have smoked for a very long time, and you suddenly stop, you will also get sick. Those who have smoked for a very long time cannot stop smoking....my brother stopped smoking and after a year, he got very ill.

Smoking cessation was alluded as causing further stress to the body and harming it in the process. Participants also responded to questions on smoking by discussing the context of stress in relation to smoking. Overcoming stress was discussed as an underlying reason regarding cigarette uptake. While other participants revealed that smoking was difficult to curb because it was a problem of "habit and addiction." Concerning "habit and addiction" participants were unaware of how to negotiate addiction behavior with some responding that "if one is not stress, they will smoke less... if they were more relaxed." Here again, alluding smoking behaviors as linked to everyday stress as lived experience of a low-income individual.

Midway through the initial discussion on smoking, a participant expressed frustration on the topic of smoking. She too, was a smoker, and another participant had called her out on her smoking behaviors. She became frustrated in the process and then strongly verbalized "dont bring up smoking to me. It makes me angry... it is my right to smoke. Don't talk about my rights" to the participant next to her. In the process, we identified the stressors and challenges of discussing smoking as a heart unhealthy behavior while at the same time recognizing the affective responses toward smoking cessation. Stress was conceptualized in multiple forms in relation to smoking. Stress referred to financial rife faced that led to the need to smoke, while at the same time, smoking also alleviated everyday stressors of dealing with financial pressures.

In another example, the discussion on smoking re-emerges with the facilitator probing what are the barriers to quitting smoking. A participant responds, "because don't have money, that is why I smoke." The facilitator laughs in confusion but pushes to ask again, "if you don't have money, how to smoke?" reflecting our privilege when thinking about the affordances of smoking behaviors from the point of view of financial accesses. From the facilitator's point of view, it was not possible to afford smoking if you did not have money, but from the participant's point of view, it is because one does not have money relating to a lack of finances that causes one to smoke. Smoking was a behavior of the deprived. If one had money, they would not need to smoke, relating smoke to stress. The stress from financial issues is central to the amplification of addiction to smoking again.

Smoking cessation re-emerged in a further focus group discussion with participants identifying the need to construct knowledge infrastructures on nicotine addiction and seeking medical help in resource-poor spaces. When asked if they have tried different techniques to curb smoking, participants shared, "I start chewing gum but it did not help my craving." In terms of knowing spaces that provided smoking cessation services, participants shared that they had not attended any, with one participant Cik Ang who located advertisements on smoking cessation services in the newspapers. Counseling sessions were also challenging because of the caregiving needs of their children and grandchildren at home. Participant Halimah went further to discuss that counseling sessions were only effective if "both wife and husband to sit down together with the counselor and discuss their financial difficulties and how much money we are spending on smoking." *Cik* Ang adds about her own husband's narrative "my husband have a heart attack and then he immediately stopped smoking after that…it is all about the mindset."

Participants shared that the only time abstinence is possible was during the period of *Ramadan* where "it is possible to stop smoking during the fasting period but after breaking fast, I will breakfast with cigarettes." Therefore, a good target for them to work with is not cessation entirely, but to reduce the number of cigarettes smoked. This led to the creation of the material on smoking cessation based on the needs of the community such accessing these resources that were available for free to break the addiction. The creation of the collaterals with the community during the focus groups are further documented in the section below on 'Culturally responsive heart health material'.

Malay Is Food: How to Eat Heart Healthy?

Malay food emerged as the richest discussion on the conversation regarding heart health. One the one hand, everyday diet was a central category; participants were most willing to address and shift. On the other hand, the limitations of how to eat healthy Malay-centric food remained absent in their understandings. This was an essential aspect of knowledge infrastructures the community hoped to build together where there were no disparate viewpoints. A large part of the conversation began with the importance of Malay cuisine to their identities and their lived experiences. The process of sharing their cuisine was a central part of the value placed on the complex and unique way Malay food is prepared, while at the same time acknowledging that aspects of its preparation could be more heart health friendly.

Food was mentioned from multiple dimensions. The identification of food as a primary barrier toward achieving a healthy heart were explained in terms of the nature of eating practices and more specifically, diet consumption. Some of the excerpts relating to food included managing food "*jaga makanan kita* (don't know how to control food)." Here participants were referring to both quantity and quality of consumption. Others asked questions that attributed poor heart health to "eating more chillies eh…oily." A participant questioned during the focus group discussions, "*belachan sehat tak* (is belachan healthy)?". *Belachan* is a paste made of chili peppers and shrimp paste as two central ingredients. The process of making it that involves grinding and then frying the grinded mixture leaves participants confused about its health appeal. Yet, *belachan* was a key ingredient in many Malay centric dishes.

Other food queries involved the nature of eating such as "eating and then sleeping," "you are what you eat," while also suggesting that the kind of food the community eats is problematic "*makanan kita* (our type of food)" known as "*malas*" the act of not performing an activity. Amid these responses, were also a reflection of the lack of knowledge on "we don't know when to stop eating…. what food to take," once again tying back to the broader theme of an absence of health information on what constitutes good heart health behaviors or how to look after once heart.

When questioned on oils known as *minyak*, sugars known as *gula* were posed, some participants acknowledge that there was little knowledge, but others mentioned that they "don't know at all." For example, participants were unable to determine how much oil or sugar to use that did not border on at levels that were not healthy for the heart.

During the discussion, the kinds of rice utilized and how to select rice that was of better quality (white, brown etc.) emerged as well. On the conversation regarding what constitutes heart healthy or unhealthy food, participants were able to identify heart unhealthy Malay food. The facilitator begins by asking, "what are heart healthy foods located within the Malay food groups"? These were described in rich detail. A Malay beef stew called *rendang* was mentioned multiple times, with a participant describing the dish as "r*endang tu* dangerous (very heart unhealthy)," while another participant discusses "*prata, mee goreng, nasi biryani, ayam goreng … tak sihat la* (all of these are dishes located in the Malay and Indian Muslim food categories that were described as unhealthy)." Another participant proposes the possibility of steaming a Malay dish named *nasi ayam,* "nasi ayam boleh steam tak?" instead of other unhealthier methods of food preparation. The mention of soups and the process of steaming food also emerged. There was a discussion on the preparation of *Singgang*, a Malay fish soup. Here participants began discussing heart healthy recipes that were Malay centered, described as "must have the Malay flavor."

One aspect of the discussion involved adopting other food groups that were outside of the Malay cuisine, such as whether or not there should be greater knowledge on eating and preparing Western-centric food groups such as yogurt, soups, and salads. All but one participant preferred navigating within these food groups for a healthier heart. One participant outrightly suggested that "I don't and won't eat western food." A few participants discussed their fear of soups while acknowledging that "tomato soup… *itu la makanan sehat* [this is healthy food]."

Other elements regarding food from a low-income perspective included access to heart healthy foods found within the household. Sometimes these included canned rations from food distribution drives. Participants also discussed the nature of food prepared for consumption over a few days. With limited resources, food was made based on what could provide them with the most considerable amount, over a more extended period, as opposed to thinking through heart healthy methods of preparation. Other types of eating included seeking out food options relating to once finances, with a participant commenting "that everyone here has financial problems so they can [meant to be cannot] buy expensive good food." Maintaining good heart health practices, therefore, was situated within the ambits of structural access and choice over resources.

Developing Heart Health Knowledge Infrastructures

Developing heart health knowledge infrastructures refers to detailing the process of developing community-centered material to conceptualizing the distribution of the content. Participants designed these during the focus group process. Participants discussed that "we want to target all the unhealthy people like us… within our neighborhood…around here la… *banyak* (many) Malay families here…can say majority ah…can say one block about 74." In trying to target their intended audiences, participants indicated several concerns, including how many of their potential target audiences were in wheelchairs and needed to be addressed to receive the collaterals through door knocking exercises.

The critical themes involved, developing collaterals to undo the information disparity currently faced by the community on heart health. These included dealing with the lack of knowledge on heart attacks, centering the differences in gender by sharing the gender variation on some of these symptoms (refer to **Figure 1**). The second involved Malay-centered heart healthy recipes tailored explicitly for heart healthy cooking in a low-income setting that often involves limited food resources (refer to **Figures 2**, **3** for examples). The third focused on smoking cessation was tailored to be directed at potential community members with the structural access that provided the necessary resources for reducing addiction behavior, The goal of the material was to assist with smoking cessation cost-effectively (refer to **Figure 4**).

SERANGAN JANTUNG

PUNCA-PUNCA SERANGAN JANTUNG
- ○ Merokok
- ○ Kencing manis, tekanan darah tinggi dan kolesterol tinggi
- ○ Tidak menjaga pemakanan
- ○ Stress

TANDA-TANDA SERANGAN JANTUNG
- ☐ Sakit di bahagian dada yang lebih dari 20 min
- ☐ Pening
- ☐ Sakit di leher, bahu, perut dan raham
- ☐ Lelah secara tiba-tiba dan sesak bernafas
- ☐ Sakit yang merebak ke bahagian kiri badan
- ☐ Batuk yang berpanjangan dan berkahak putih/merah
- ☐ Peluh sejuk
- ☐ Kaki dan buku lali yang bengkak
- ☐ Rasa mual/ Muntah
- ☐ Degupan jantung yang terlalu cepat

TINDAKAN JIKA BERLAKU SERANGAN JANTUNG
1. Telefon **995** dengan segera
2. Lakukan CPR
3. Jika menunggang/memandu, berhenti dan minta pertolongan
4. Makan aspirin jika anda tidak alergik.

ANGIN AHMAR

PUNCA-PUNCA ANGIN AHMAR
- ○ Saluran darah yang tersumbat dan darah tidak sampai ke otak
- ○ Sel otak mati dan otak rosak menyebabkan kehilangan memori atau hilang keseimbangan.

TANDA-TANDA ANGIN AHMAR
- ☐ FACE (MUKA)
  Suruh individu itu untuk tersenyum. Adakah senyumannya senget sebelah?
- ☐ ARMS (LENGAN)
  Suruh individu itu mengangkat kedua-dua tanganya. Adakah sebelah tangan jatuh?
- ☐ SPEECH (PERCAKAPAN)
  Adakah individu itu boleh mengulang ayat mudah?Adakah percakapannya tidak jelas dan susah difahami?
- ☐ TIME (MASA)
  Setiap detik sangat kritikal bagi pesakit strok. Masa untuk pulih dari serangan strok terhad iaitu kurang dari 4 jam dari serangan. Setiap saat yang berlalu, semakin banyak sel otak yang mati.

TANDA-TANDA MINI STROK

Mini strok yang berlaku akibat saluran darah yang tersumbat tetapi hanyalah buat sementara. Mini strok adalah isyarat bahawa individu boleh mengalami serangan strok di masa akan datang.
- ☐ Mulut/Pipi sebah
- ☐ Sukar bertutur & menelan
- ☐ Hilang Keseimbangan badan
- ☐ Pemandangan kabur
- ☐ Pening kepala yang teruk secara tiba-tiba
- ☐ Letih secara tiba-tiba
- ☐ Anggota badan mati seketika

Saya mungkin boleh elak dari terkena strok jika saya menjalani gaya hidup sihat dahulu.

FIGURE 1 | Symptoms of a Heart Attack & Stroke.

FIGURE 2 | Heart Healthy Soup.

SUP CENDAWAN DAN UDANG

BAHAN-BAHAN

1 sudu besar minyak
3 biji bawang merah, dihiris
3 ulas bawang putih, dihiris
1L air
350g cendawan tiram
100g udang
1 batang lobak merah, dipotong dadu
Garam untuk menambah rasa
Daun bawang dan daun ketumbar, dicincang, untuk hiasan
Optional: Sebiji Telur

CARA-CARA

1. Panaskan minyak di dalam periuk dan tumiskan bawang merah dan bawang putih sehingga harum.
2. Masukkan air, cendawan, udang and lobak merah dan masakkan sup sehingga mendidih.
3. Jika ingin pekatkan sup, masak sebiji telur sewaktu sup mendidih.
4. Tambahkan garam untuk rasa. Hiaskan dengan daun bawang dan daun ketumbar.

Elakkan dari menggunakan minyak goreng yang sama lebih dari dua kali. Minyak yang sudah diguna harus disimpan dalam peti sejuk agar bakteria tidak tumbuh.

Credit: Nutrition & Dietetics, Khoo Teck Puat Hospital

FIGURE 3 | Recipe.

Channel Identification

A vital part of the discussions were in identifying mediums and channels for sharing the community-built knowledge infrastructures. There were extensive discussions regarding medium and channel use. Again, using a culture-centered intervention meant community members at the grassroots fundamentally identify the kind of channels they use to receive, seek, and share health information. Much of the heart health literature exist in spaces that are hard to access for low-income communities. These include heart health material online, mobile phones, social media, and other digitally unequal mediums. The elderly in Singapore remain excluded from the consumption of information communication technologies (ICTs) unable to familiarize themselves with the constant pace at which new technologies emerge and change (Tan and Chan, 2018). Gender and socioeconomic disadvantages also impacted technology use in Singapore (Cheong, 2007). Low-income and more specifically, low-income elderly participants had the least access to these resources on ICTs (Ee, 2012).

In working through the solutioning of challenges toward access heart health material, printed material remained the top choice for participants. Grassroots and local events were also highlighted as necessary in spreading information about heart healthy resources. Keeping to the tenets of the CCA, the best channels for information dissemination were determined by the participants as well, seen as experts of their communities. These included placing pamphlets that were meant to be placed in letterboxes were delivered through door-knocking instead. Participants discussed how a key strategy toward disseminating the heart health information meant ensuring immobile elderly were also receiving this information.

The process included a vibrant discussion on channels for health information seeking. Some participants suggested posters, but it was collectively agreed that the "posters would be torn up" and, therefore, would not allow for longer-term access to information. Pamphlets remained popular, but the discussion also highlighted the problem of disseminating pamphlets through letterboxes that would have good outreach. However, the participants also noted that the "*letterboxes all lock la*" therefore, limiting its reach. Members then shared the possibility of handing out these materials through word of mouth and community members. "SMS second choice" was discussed for sharing Malay centric recipes, referring to text messaging. However, they were concerned about the lack of mobile phone use, especially among the low-income elderly. Finally, participants reiterated their need for accessible channels and these included brochures and pamphlets that they could store

BAHAYA MEROKOK

- Risiko kepada **penyakit jantung, serangan jantung** dan **strok**
- Penyakit paru seperti bronkitis kronis
- **Barah** paru-paru, mulut, leher & hidung
- Risiko hidapi **kencing manis**
- Pengedaran darah yang kurang baik

BAHAYA MEROKOK PADA IBU HAMIL

- Setiap kali ibu menghidu asap rokok, bayi akan sukar untuk mendapat udara darinya
- Bayi akan **sukar bernafas** yang menjejaskan paru dan otaknya
- Bayi boleh dilahirkan dengan kecacatan seperti **bibir sumbing** dan **paru yang lemah**
- Bayi bermungkinan lahir tidak cukup bulan

TIPS UNTUK BERHENTI MEROKOK

- Kenali simptom-simptom anda dan buat persiapan (contoh: jikalau anda suka mengerakkan tangan-ke-mulut, gunakan inhaler nikotin)
- Tetapkan tanggal berhenti yang penting bagi diri anda
- Jangan membeli lebih dari 1 paket rokok untuk disimpan di rumah/tempat kerja
- Sediakan satu tabung dan denda diri anda sekiranya anda merokok lebih dari sepatutnya

"Saya kurangkan merokok dengan menyibukkan diri dengan membuat kerja sukarelawan." -En. Rais

SIMPTOM KETIKA MENGURANGKAN MEROKOK

- Fisikal: batuk, flu, sembelit, pening kepala, cepat letih, pernafasan sesak
- Psikologi: panas baran
- Berat badan mungkin meningkat akibat mengidam makanan

FIGURE 4 | Information about Smoking Cessation.

and distribute efficiently to other community members via word of mouth.

Culturally Responsive Heart Health Material

In discussing the building of knowledge infrastructures to close the information gap on heart health, participants wanted to address three aspects. These were issues on smoking, closing the knowledge gap on heart health, and designing heart healthy Malay centric recipes. All of these needed to be accessible to their cultural and structural capacities. What this immediately meant was that the material could not be produced in English and it was instrumental to center the Malay language in the published content. In designing these materials, visuals were indicated as helpful in their understanding instead of the mere use of words. Concerning the generation of recipes that were heart healthy, for example, participants discuss "drawing the ingredients as opposed to writing them out," reflecting a visual need to understand healthy ingredients. Keeping these factors in mind, our production designer worked with the community to go and back and forth with the designing of the collaterals.

Symptoms of a Heart Attack [Figure 1]

Figure 1, titled as "*Serangan Jantung* (Heart Attack)" and "*Angin Ahmar* (Stroke) formed the central component of the poster featuring elderly community participants as the key visual representations that would communicate central elements of the heart health message. This related to community members as central in identifying with the visual material and navigating the heart health information in a discernible way. The poster systematically depicted how to recognize and connect heart attack and stroke symptoms clearly, describing them in Malay through an interaction of visual and text. At the bottom of the poster, it provided vital contact information and what to prepare once a heart attack is identified. The two individuals featured in the poster were community-identified figures. Participants in the discussions voted among themselves to identify participants that will be featured in the material.

Malay-Centric Heart Healthy Recipes [Figures 2, 3]

Figures 2, **3** are examples of how the community specifically addressed eating heart healthy while factoring into account the low-income context of food resources. For example, **Figure 2**

is the overview of the recipe offered, followed by **Figure 3** that provides that ingredient list and preparation techniques. Especially striking when adopting a participatory process was identifying positive deviance among Malay community members that were already preparing heart healthy meals. Researchers worked with these various community members to develop Malay-centric recipe guides from participants that were already practicing heart healthy cooking of Malay dishes. These recipes were discussed among researchers, community members, and the production designer. Ingredients were substituted, depending on the kind of food resources community members could access, while at the same time keeping the recipes heart healthy. Recipes acted as simple frameworks for heart healthy Malay-centric recipes where community members were able to substitute the basic ingredients if they were inaccessible. The recipes presented kept to the participants' need for "Malay flavor" that referring to the community's need to ensure Malay spices and techniques were engaged in the recipe design, while at the same time remained healthier options compared to other cooking techniques typically used in the preparation of Malay cuisine. These recipes ranged from a Malay porridge recipe, soups, and healthier version of fried rice that had reduced salt and more vegetables.

The recipes also featured the *makciks* (aunties) who constructed them during the focus group discussions. These dishes displayed are commonly prepared across Malay households, and the women adapted them to their families' needs. Here the women exercised their agency by sharing these recipes and then designing them in a way that is both resource and heart health accessible. In honoring their contribution, they displayed the recipes and themselves in the collaterals. Ownership and empowerment were central to the CCA process and their displays in the collaterals honored their authorship of these recipes.

Smoking Cessation [Figure 4]

Figure 4 was aimed at building and connecting informational resources on smoking cessation for community members. The title "*Berhentilah Merokok Sebelum Terlambat* (Stop Smoking Before It is Too Late) was the crux of the tagline of the poster with three different representations constituting the face of the poster. As discussed, participants identified smoking as problematic across various community members and wanted different faces that represented potential target audiences in the community. The first red box on the top left featuring a Malay male detailed the dangers of smoking known as "*Bahaya Merokok.*" Just below the figure of the Malay male, the risks of smoking for pregnant mothers "*Bahaya Merokok Pada Ibu Hamil*" were highlighted detailing the effects on how smoking has an impact on the unborn fetus and young children. The other details in the poster included tips on how to stop smoking include some of the symptoms faced during the cessation period. These suggestions helped participants better understand how the body reacts during different periods when curbing the addiction. For participants, cessation could only happen if they were able to access free resources. Thus, researchers' located various health infrastructures across the island that provided these services. The free services for smoking cessation were highlighted in the content as well-indicated as "*tempat tempat tersebut menawarkan kaunseling peribadi bahan-bahan pendidikan dan sesi* (the venue offers personalized educational counseling and follow-up sessions during the process).

Post collateral development, community members then came together to organize a launch event with a clear objective of sharing, disseminating, and explaining the collaterals designed. Again, all members from the low-income space were invited including Chinese and Indian neighbors. The participants themselves distributed the invites. The campaign launch was titled, "Healthy Cooking" where the slogan for the entire campaign was "*berjaga-jaga sebelum terlambat* (take precaution before it is too late)" (**Figure 4**). The launch event was made possible through collaboration with the local community citizen center. Participants turned volunteers cooked healthy Malay recipes that were developed during the focus group discussions that included "nasi goreng (fried rice), bubur terigu (porridge)" among others.

Hundred community members attended the event with most of them above the age of 45 and an approximate 70% attendance of Malay individuals. The launch began with the distribution of brochures and postcards of which the focus group members had tried and tested (**Figures 1–4** are examples). All of these materials developed and designed through the focus group process. Participants and facilitators provided a short talk in Malay explaining the collaterals and also spent time addressing a question and answer session. In the process, the manager of the citizens' corner translated the material for Chinese attendees and shared with them the nature of the collaterals in Mandarin. Focus group participants orchestrated simple games to facilitate greater interaction to ease comfort, to get participants to participate in answering questions on heart health located in the collaterals. The event specifics were chaired discussed by participants at the focus group meetings. The event was initiated and organized by community members to launch the material designed and developed.

DISCUSSION

The most salient aspect of adopting a culture-centered health intervention is identifying the ontological limits of how participants framed heart health. In this study, the absences began from the very concepts and categories of what heart health entailed (coronary heart disease), depicting the lack of culturally grounded information architecture within the communities. In recognizing these absences, it became necessary to negotiate the definitional terrains in which academics work on/from. In selecting the meta-theoretical frameworks of the CCA to address health promotion in marginalized settings, the material realities of disenfranchisement connect to the everyday cultural and local meanings. A culture-centered intervention, therefore, provides the theoretical and methodological lens toward inverting the dominant power dynamics of health experts. Culture-centered readings on the knowledge gap reshape the definitional terrain, offering anchors to deep reflexivity about how "health problems" are framed for the margins. Lupton (1994) cautioned the lack of responsiveness to health promotion that fails to acknowledge and respond to the cultural context in which health meanings, understandings, and lived experiences are based. The culture-centered intervention tries to address this gap by paying attention to the socio-cultural environments where health promotion campaigns target.

While a similar heart health study was located by Kandula et al. (2012) for South Asians in America facing disparities in heart health, it did not utilize the fundamental tenets of a structure, culture, agency approach of the CCA. Heart health material were constructed for cultural targeting to the underserved South Asian population using pre-designed expert centered CHD material. The health promotion material remained biomedically framed. Changing the language of the material fails to pay attention to the various dimensions of culture and structure that limit participant negotiation in locating their health meanings. In community-based heart health research from a top-down information dissemination perspective, the assumptions regarding the meanings of heart health are already pre-defined for participants by research teams (e.g., Kandula et al., 2015). Participation then takes place through the negotiations of terminologies and meanings that have already been pre-configured and well-conceptualized. The biomedical literature discusses the heart from the cardiovascular, while at the same time continually tries to make sense of how modifiable lifestyle factors afflict the cardiovascular system.

In a seminal piece, the Dutta (2007) delineates how a CCA process is different from culture-sensitivity approaches conducted by Kandula et al. (2012). The participatory process in such studies causes no shift in the power dynamics of the researched. The locus of control held by experts vs. the community is often a central difference between a CCA study from a culturally sensitive approach (Dutta, 2007). Even though Kandula et al. (2012) and Kandula et al. (2015) study on heart health proved effective in addressing heart health risk factors based on a randomized controlled trial, it did not push for participants to take charge in the process of participation. Evaluating a CCA intervention is primarily based on centering community voice, undoing co-opted participatory practices, and democratizing power in health settings.

COMMUNITY GROUNDED HEART HEALTH MEANINGS

Community voice suggests that the spectrum of understanding of the cardiovascular system works through a different set of interpretations. The heart is viewed as a holistic system rather than the delineations based on modifiable and unmodifiable risk factors that result in poor heart health conditions. A study with African Americans where stress from structural racism contributed to heart health disparities, reveals the different interpretations and understandings of heart health challenges (Dutta et al., 2019). These articulations undo the hegemonic imposition on the framing of CHD. Yet, when participants take control of the research process, CHD meanings are refashioned, where CHD becomes a problem of limited choice and structural disadvantage. The language of lifestyle factors is challenged when participants conceptualize how behaviors are often far from agentic, removed from their ability to make any real lifestyle choices (Kaur, 2018).

Similarly, in the Singapore heart health study, creating culturally focused heart-healthy food choices remained insufficient in the articulations of low-income Malay community members. Community members needed the building of Malay-centric heart-healthy knowledge that would also center their financial and resource allocation challenges as central to their lived experiences and outcomes with heart health. In another example, smoking behavior, especially within low-income spaces, remained a site of active contestation locally. Even within the focus group discussions, smoking behaviors, and heart health often led to heated conversations. While many recognized that smoking behaviors were detrimental to health, smoking behaviors were also tied to managing everyday stress in the low-income context. National discourses have often vilified smoking behaviors among low-income individuals in connection to limited welfare provisions. Kaur (2018) discusses this further in a qualitative study on heart health meanings among low-income Malays,

> "the purchasing of cigarettes by low-income participants are often viewed contentiously by actors of welfare provisions. Many see the consumption of cigarettes by low-income participants as a narrative that comes into direct tension with how needy participants are supposed to live. Our dominant assumptions of low-income participants manifest in particular ways that disallow us from interrogating their lives in complex ways" (p. 149).

This reference sums up the debate by structural actors on cigarette consumption and aid. In our focus group discussions, the analysis of cigarette consumption was far more complex and contested. Community members read cigarette consumption from various perspectives. For families, a smoking family member was embedded within relationships of care. Moreover, the behavior of smoking itself was situated amidst the multiple forms of stress created by structures and embedded within the structures. The understanding of smoking located in the realm of everyday stress, transformed the decontextualized construction of smoking behaviors as individual lifestyle choice, instead of constructing it as a behavior tied to stressors in the life of a low-income person, the negotiations of livelihood, and the struggles with making a living as a low-income individual in Singapore.

As detailed in the discussion on smoking cessation, a fundamental part of the process entailed locating centers and clinics that provided free services to assist with addiction behavior. Therefore, moving beyond just knowledge provision, but also identifying potential structural resources that could support community members in their negotiations of heart health. This led to the creation of structurally responsive materials that would assist community members in navigating the complex and unstructured distribution of heart health information in a culturally situated way. A structurally responsive intervention meant interrogating the deep relationship structure shares with culture in limiting access to resources. Community-based participatory research, for example, may construct responses that are community-centered, detailing cultural-sensitive ways to navigate health outcomes. A culture-centered intervention on the other hand, is situated at the structure, culture, agency nexus, thus reading both the enabling and limiting aspects of structure, locating community-driven solutions that are within a local understanding of a community's health behaviors and outcomes.

LIMITATIONS AND CONCLUSION

Our approach to Malay Heart Health began by identifying localized articulations of heart health and building the knowledge capacity of the community by designing heart health scripts with the community. In the solutioning process, community voice centered as a key anchor toward the process of building these scripts. What remained a challenge with limited funding resources were opportunities to push the intervention further to include other themes that were identified, including building capacity for physical activity. Outreach remained challenging as well, with community members unable to participate in the discussions due to work schedules, caregiving, and disability issues. This meant that certain voices in the margins remained further disengaged in the process. Male participants in the study remained marginal as well. The participants in our research had also wanted greater engagement with Malay experts on nutrition and diet to further assist with the tailoring of Malay heart healthy recipe collaterals. Despite these challenges, participants took ownership and carried on learning and preparing new heart healthy Malay recipes at the local citizens' center located within the rental flat estates. Due to budget and funding issues, we were unable to tackle all the themes proposed by participants in the research process. Other limitations include the site of the study. The site of the study was narrowed to a specific physical location in Singapore. This was a mature estate [older residential estate] where Malay community members have lived for an extensive period and could potentially comprise an older low-income Malay population, leaving out other age groups belonging to the low-income space.

Other limitations also include the interlocuter's translation and interpretation of the voices of our participants during the focus group sessions. While all care was ensured such that the subjectivity of the researcher was limited in the relaying of the data, it must be mentioned that the interlocutor was not a cultural insider to the community. Despite Malay being the interlocuter's second language, specific meanings of lived experiences often required clarification. On page 13 (paragraph three), we see the challenges of dialogue between the interlocuter and the participants on the topic of smoking. This conversation required going back and forth to ensure participant voice was centered in the meaning-making of heart health understandings. To limit subjectivity, the interlocuter would provide constant clarification throughout the focus group with participants, before translation.

In the CCA process of participation, ownership was central toward empowering communities toward the sustainability of the broader goals of the project. Key learning from the participatory process is that communities are not passive toward heart health outcomes and were in fact, empowered to change their lived experiences with heart health disparities when they were actively involved. The participatory openings for participants to develop health knowledge also invert the presentation of illness by expert actors, demystifying biomedical language as the only framework for making sense of disparities from agentic health behaviors. The hegemonic production of heart disease requires critical interrogation for rendering a single story on individual behavior as a site of health behavior change.

DATA AVAILABILITY STATEMENT

The datasets generated for this study will not be made publicly available due to the vulnerability of the participants as per IRB approval clause.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by National University of Singapore IRB. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

All authors have contributed to both the research process and writing of the paper.

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En Nuestra Casa No Hay Chinchorros: A Youth-Oriented, Participatory Approach to Chagas Prevention in Guara, Loja Province, Ecuador

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Chagas disease is a neglected tropical disease that disproportionately affects impoverished rural communities. Insecticide-based approaches are inconsistently performed and exorbitantly priced for the communities affected. The present study considers an alternative approach to primary prevention of Chagas disease using entertainment education. As part of an ongoing effort in rural Ecuador, we worked with the children of the community of Guara, national insect control workers, and academicians to co-develop a song to promote behaviors related to preventing Chagas. Through an analysis of the song, we demonstrate opportunities for meaningful intervention in rural communities, as well as challenges to implementing an entertainment education approach when working with national stakeholders.

Keywords: Chagas disease, song (or singing), community-based participatory, entertainment education strategy, rural comminitites, Ecuador (country)

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INTRODUCTION

Chagas disease is a disease caused by *Trypanosoma cruzi*. This parasite infects ∼6–7 million people, mostly in the American Continent (WHO, 2018). The main route of transmission of this parasite is via the infected feces of Triatomine bugs. Triatomine bugs, known as "*chinchorros*" or "*chinches*" in Ecuador (and by other names in other places), feed on the blood of mammals, including humans, and defecate near the site of the bite. People introduce the infected feces into the bite site, eyes, or other mucosal surfaces when they scratch. The parasite gains entry to the bloodstream and infects many organs. The initial infection can be asymptomatic or present with non-specific symptoms, such as fever, malaise, headache, or lack of appetite. When present, these disappear within a month or two; however, low-level infection remains in certain organs, such as the heart and the nervous system. The continuous, albeit slow, destruction of the tissues by the parasite, compounded by the patient's own immune response, causes damage to the tissues. Over 5–20 years, these changes remain unnoticed, until the damage is such that apparent chronic symptoms of Chagas disease appear. Progressive debilitating heart disease occurs and can lead to disability or death. In addition, the parasites can destroy the neurons that control the movement of the digestive system. This causes a progressive enlargement of the esophagus or colon. Known as mega syndromes, the massive size of the these organs results in difficulty swallowing, chronic constipation and, due to the volume they occupy in the chest and abdomen, can severely interfere with normal cardiorespiratory function (WHO, 2002).

Chagas disease is endemic in Loja Province, located in southern Ecuador. This province has one of the highest poverty rates in the country (INEC, 2010). Triatomines were found in 68% of communities located in sub-tropical areas of the province (Grijalva et al., 2015). In some communities, infestation of houses reached up to 48%. Outside of the house, bugs colonize chicken nests, Guinea pig pens, rodent nests, and places were domestic animals rest. Inside the home, bugs are often found in the bedroom, in deep cracks found in adobe walls, under the mattress or bedding, or under accumulation of clothes or other items near the bed. It is not uncommon for chickens or guinea pigs to be kept inside the house for protection. In these cases, bugs are commonly found where they nest or sleep. Control programs rely on insecticide spraying of the houses by personnel from the National Chagas Control Program and community education. However, due to the presence of wild populations of bugs associated with squirrel and bird nests (Grijalva et al., 2012), frequent reinfestation of the houses occurs soon after the residual effect of the insecticide subsides (Grijalva et al., 2011). Moreover, while most of the population is aware of the presence of bugs in their houses, they do not know that "chinchorros" can transmit Chagas disease. Due to lack of allocated resources and political decision, visits by the control program personnel to rural communities in Loja province are infrequent. Therefore, knowledge about the dangers of having bugs in and around the house, how the disease is transmitted, and what the inhabitants can do to protect themselves is paramount to prevent transmission (Patterson et al., 2018).

Because Chagas disease is largely invisible, and because there are few effective treatments, primary prevention is necessary. Primary prevention is an intervention that occurs before a health effect occurs, such as vaccination, elimination of substances known to be associated with a disease, or through altering risky behaviors (Reisig and Wildner, 2008). Unfortunately, because it is a neglected tropical disease, a disease that affects economically and geographically marginalized people, there is a long history of systemic underinvestment in efforts to prevent the transmission of Chagas disease (Molyneaux et al., 2016). In the present study, we discuss one communication intervention that attempts to promote primary prevention of Chagas disease. Specifically, working with children in the community of Guara, a small community in Loja Province, Ecuador, we co-created a song that raises knowledge of easily implemented home-based practices that can prevent infestation by triatomine bugs and, thus, reduce exposure to the vectors for Chagas disease. We begin with a discussion of our approach, an approach based in principles of Entertainment-Education with an emphasis on the song tradition. We then discuss the creation of the song to promote behavioral changes regarding Chagas and provide an analysis of this song and its messages. Finally, we offer some implications that this co-participatory process has for implementing Entertainment-Education strategies in the context of neglected tropical diseases.

ENTERTAINMENT-EDUCATION AND PERFORMANCE FOR SOCIAL CHANGE

Entertainment-Education (E-E), is a field devoted to using entertainment such as large-scale media (films, broadcast, radio, and television programs) and live performances for education. E-E scholars all over the world have done research on various entertainment programs, and how these programs have educated audiences and have supported pro-social change (Sabido, 1989; Wallack, 1990; Nariman, 1993; Piowtrow et al., 1997; Singhal and Rogers, 1999). Some of these programs are purposely designed by change agencies; other programs that were produced just for entertainment have had unintended positive effects on audiences' thoughts and behaviors. The success of these programs has inspired governments and non-profit organizations to purposefully design entertainment-education projects.

A classic example from Latin America often cited by E-E scholars is the telenovela "*Simplemente Maria*." *Simplemente Maria* showed a young woman who achieved success by learning how to read and to sew. Researchers say that, as a result of *Simplemente Maria's* popularity, literacy classes became very popular in Peru and the Singer sewing machine's sales broke records (Simplemente absurdo, 1970; Vasquez, 1970; "Simplemente Maria" se acabo, 1971; Singhal et al., 1994). E-E scholars have also cited the popularity of Miguel Sabido's (1989) Mexican soap opera as *Ven Conmigo* Population Communication International's Indian soap opera *Hum Log* (Singhal and Rogers, 1988). In addition to studies of classical cases of E-E, many recent projects have used Entertainment-Education for change (Communication Initiative, 2011), including efforts in India to promote HIV/AIDS awareness (BBC, 2006), in Colombia to support healthier sexualities and gender relations (Igartua and Vega, 2014), and in Ukraine to address the dangers of land mines (Prokhorov, 2018).

NON-BROADCAST ENTERTAINMENT-EDUCATION THOUGH PERFORMANCE

One weakness of E-E scholarship, however, is that most E-E scholarship has focused on broadcast media such as television and radio or on music albums. Live performance, such as songs and theater performed among community inviting direct audience participation, has less often been researched or discussed. However, scholars of "performance theory" or more specifically, "performance for social change" have attended to various performances projects that have tried to educate and bring directed change in their audiences' thoughts and behavior. Dwight Conquergood (1988), a leading theorist of performance studies states:

> …deCerteau's aphorism, "what the map cuts up, the story cuts across" also points to transgressive travel between two different domains of knowledge: one official, objective, and abstract-"the map"; the other one practical, embodied, and popular-"the story." This promiscuous traffic between different ways of knowing carries the most radical promise of performance studies.

> Performance studies struggles to open the space between analysis and action. (p. 1)

Enacting this paradigm, Conquergood (2002) directed and helped to design live performances in a Hmong refugee campaign in Thailand. Specifically, Conquergood (1988), with his team, produced skits and scenarios drawing on Hmong folklore and folk singing to develop awareness about health problems. Following Conquergood, Sharma (2012) designed and directed a live song and theater campaign in the state of Uttar Pradesh in India. The campaign developed 15 scripts containing health message in different song and theater genres of Northern India, and more than 150 professional troupes were trained to perform these scripts.

In Latin America, entertainment-education through performance (theater songs, and other forms) has a long history. Latin America may be the place where live performance is used the most to educate and effect thought and behavioral change. As early as the 1970s, the University of California Los Angeles' Latin American Center "document[ed] and analyze[d] the role of the theater and other dramatic and paradramatic arts, such as cinema, television, dance, and song, as pedagogical tools for literacy and health campaigns, occupational and citizenship training, and also as motivational agents for social change" (Luzuriaga, 1978, p. 11). According to this research, performances (in its various forms) have played important educational role over the course of the Latin American history from the time of the Incan Empire to the present. Drawing on this tradition, *teatro infantile,* or "the theater for the children," has been widely employed by ministries of education all over Latin America, and many plays for children, which were educative but "mainly" entertaining, were published. *Teatro Infantile* was also used in teaching children and also to educate them in social attitudes and ideologies much beyond the overt social issues (Luzuriaga, 1978).

Since 1960s, Paulo Freire's philosophy of *concientización* or *critical pedagogy* discussed in his books, (Freire, 1970, 1973), has influenced Latin American Theater for social change deeply in Brazil, Chile, Colombia, Argentina, Peru, and other countries. Freire argues that an education that emphasizes critical thinking and awareness is the only way to liberate the oppressed people. Theater scholars and directors, such as Augusto Boal and Enrique Buenaventura (Luzuriaga, 1978), have used Freire's philosophy in their theater and performance work for education. Buenaventura worked on the method of "collective creation," which is also known as *Buenaventura Method*. In this method the play is written collectively by the participants, rather than following the usual text-director-performers-process, which has a designated playwright and a director who directs designated performers (Luzuriaga, 1978). This method of performing for education and social change has become very popular all over the Latin America. One of Boal's (1993) experiments in popular theater was done in Peru where theater was used as a part of an official literacy campaign called ALFIN (Peración Integral). The campaign was based on Freire's pedagogy. In this project, along with theater, Boal also used other participatory methods such as photography and the puppet theater. Boal showed through this campaign that theater can be used as self-expression by the oppressed, and can help them to change their outlook from passivity toward things to the one of active participation and dramatic action. Boal called this kind of theater as truly educational or the "the theater of conscientization."

This use of theater and other performance modalities for education has been since been very popular in the Latin America (McCarthy and Galvão, 2004). Through the work of these performer-thinkers, we see that there are local traditions of using performance, bringing awareness, and educating masses about political and social issues in global South. This work is distinct from the dominant Entertainment-Education initiatives supported by organizations situated in the first world or the global North.

THE USE OF THEATER AND "SONG" TRADITION FOR EDUCATION AND SOCIAL CHANGE IN LATIN AMERICA

The Use of Songs

Latin America is one of the few places where the "song" tradition has a very distinct place in the performance landscape and been used for social and political education and change. In the 20th century, almost all countries in Latin America have had their own "new song" movements that started in response, and in support of, progressive change. Examples include: "Nueva Canción Chilena" (Chilean New Song); "Canto Popular" (Popular Song) in Uruguay, and "Movimiento del Nuevo Cancionero" (the New Song Movement) in Argentina. The new song movements originated in 1950s, 1960s, and 1970s during a profound time of social change, including the Cuban revolution and guerrilla movements in Argentina, Uruguay, Peru, Colombia, and most of Central America, and resistance to the socialist regime in Chile (Villa, 2014). However, the effects of these song movements for change has continued to impact the communication for educating people about new issues in Latin America to the present. Shaw (2014) argues:

> Song can help give a voice to a people who otherwise are not heard, can help to amplify that voice, and can help create solidarity. By merely proposing questions pertaining to our circumstances, a song has the power to shift people's consciousness and create a vision for a better world. So though a song's reception is unique to each listener, there is potential for a communal experience. (p. 1)

"Song" can be an ideal medium for people to raise community issues such as health and social behaviors in front of their own community, as it is a medium is that combines lyrics, melody, and rhythm located in a specific place and moment in time to prompt community engagement, promote retention of the messages, and to speak in the language of its audience (Shaw, 2014).

Thus, song can get audiences to understand and remember the messages in a very effective way. Many musicians have used song to call their audiences' attention to social, political, and educative issues in Latin America (e.g., Blades, 2009; Brown, 2010; Brown et al., 2010). In addition to songs that are written to appeal across sections of society, other artists choose to target specific subpopulations that they feel can enact change, for example, rapper Tijoux's (2012) appeal to students in Chile or Zapotec rapper Mare's (2012) address of indigenous women in Mexico. Many scholars have tried to analyze the work of various artists and their songs in different Latin American countries in the context of socio-economic change, including Puerto Rico (Esterrich, 2014), Brazil (Chidester and Baldwin, 2014), and Mexico (Corona, 2014). Others have examined how song addresses specific issues like environmental degradation in Costa Rica (Ureña, 2014), youth issues in Argentina, Chile, and Peru (Balabarca, 2014), and resistance to imperialism in Cuba (Shaw, 2014). Thus, we see the tradition of "song" has been widely popular in Latin America to educate communities for change.

As community-based researchers and activists who believe that communities must be involved in their own social change, we believed that the song tradition was a strong and effective platform for continuing our work. Indeed, although they have not been subject to formal analysis, the potential for songs to be used in the fight against Chagas Disease has been recognized, for example, in local projects, such as Manos Unidas's efforts in Canton El Pinalito, Santa Ana (FUNDASAL – EL SALVADOR, 2010) and Medicos Sin Fronteras's work in Olopa, Chiquimula (junnaka, 2006), both in El Salvador, as well as Leo Messi and FC Barcelona's use of "Las palabras no dan miedo" ("Words are not scary") in their efforts to raise awareness of the disease throughout the Spanish speaking world (FC Barcelona, 2016). Each of these groups has used song to promote awareness of the dangers of Chagas disease. Drawing on this tradition, and song's record of promoting participation in the creation of messages to promote health, we engaged in a co-participatory message design process to create a song with children to promote Chagas disease prevention.

Our Positions in This Tradition

It would be important here to mention that we, as authors and activists, believe and belong to a bottom-up local paradigm of performance that originates from community, and from the performers, writers, and directors working with local people. The first author of this study first trained as a rhetorical scholar who examined texts as others had produced them. Informed by principles from communication activism, he has increasingly seen the role of rhetorical scholars as producers of texts for social impact. Moreover, drawing on a community asset-based development perspective, he seeks actively to set aside deficit-based perspective he learned in the Global North to emphasize strengths within communities and the voices in those communities that express those strengths. The second author of this essay is a fifth-generation folk performer belonging to the *Swang* (musical theater) tradition of northern India. His father is a renowned *Swang* artist, and the second author grew up performing with his father and other socially engaged performer/writers and directors. The third and fourth authors are citizens and scholars from Ecuador. They have worked with members of rural communities affected by Chagas disease in Ecuador for nearly two decades. Although trained as a biological scientist, the third author has increasingly turned to audio and video production to tell stories of people in the community and to document the work performed by our study group by and with community members. The fourth author, also a biological scientist, first engaged members of the community through standard clinical approaches; he performed blood draws, examined the samples for parasites, and reported the results to the Ministry of Health. After realizing that this top-down approach did not necessarily equate to government action within highly impacted communities, he turned to more participatory and community-centered approaches to both the investigation of and proposing solutions to socioecological factors identified by community members as essential to primary prevention of Chagas disease.

CO-PARTICIPATORY MESSAGE DESIGN PROCESS

The Government of Ecuador and the Provincial Government in Loja have longstanding programs to bring pesticide spraying to homes. These programs, however, require that individual families admit workers from the Servicio Nacional de Control de Enfermedades Transmitidas por Vectores Artrópodos (SNEM: National Service for the Control of Arthopod Vectors of Infectious Disease) and its successor agencies into their homes. The idea of addressing home access through children's attitudes was articulated by the fourth author in May 2010. The third and fourth authors consulted with approximately a dozen school teachers, more than 20 Ministry of Health workers, and other individuals in the communities who interacted with youth to investigate the messages that would be most likely to help children learn to identify the triatomine bug and to encourage their parents and other caregivers to work toward the prevention of infestation (unpublished). The recommendations included avoiding technical jargon, the use of vernacular expressions common to the rural population on this region of Loja province and the use of active learning tools to impart the knowledge to the children in the communities. This consultation process also led the authors think that a different approach was needed to attract the attention of children and, consequently, promoting their active role in the prevention of Chagas disease in their households. While this consultation in June 2010 was useful, the third and fourth authors did not feel that they were making much progress in identifying word choices or messages that would be persuasive to the children.

Therefore, facilitated by Ohio University and Pontificia Universidad Católica del Ecuador students, the third and fourth authors turned to the children themselves to shed light on what the most significant messages for the children would be. After engaging in a community and verbal parental consent process approved by the institutional review board of Ohio University and the Comité de Ética de la Investigación en Seres Humanos at Pontificia Universidad Católica del Ecuador, the research team began to work with 10 children ages 6–12 to design messages. In Loja province, specifically the communities of Chaquizhca and Guara, the third and fourth authors (along with students from both Universities and staff from SNEM and the larger project) visited with children in their schools and homes. The team sought to record the children's impressions of what constituted a healthy home, what people could do to make their homes healthier, and how insects played a role in keeping children and their families healthy. Many of the children were initially shy or afraid of the research team, but, after engaging in constructive play and with the presence of parents and teachers, the children opened up and articulated comments on each issue. Significantly, although parents and teachers were present, they were not included in the generation of ideas for how to communicate these messages. The children identified the best way to help them learn more about the insects. Specifically, they said that a song that they could easily learn would help them remember important things about preventing the insects' infestation.

All 10 children in the school were invited to participate and permission was given by their parents for their participation. There were no incentives given for participation, and no parents remained for the further activities with the children. Supervised by the schoolteacher, the research team then met in the classroom with ten children from Guara School for several hours where they first watched an educational video and worked with a booklet related to Chagas disease. The booklet included factual and cartoon-based information about the disease and activities such as cut and paste, number coloring, word-soup, and labyrinth aimed to reinforce knowledge about the Chagas disease transmission and preventive actions that can be undertaken by the family. Finally, bilingual members of the research team engaged the children in active conversation in Spanish regarding what the children considered the most important messages. Field notes were taken during this activity.

Three key issues that deserved attention emerged: identifying the presence of insects in the home; promoting awareness that they were biting insects; and, naming practical behaviors that could prevent infestations. Once the critical issues for preventing triatomine infestation were identified, the research team organized a song around these themes. For each issue named by the children, subject matter specialists from the team contributed advice. These specialists included infectious disease researchers (5), physicians (2), public health experts (2), and governmental workers (2). The subject matter experts assessed how prevalent the health practices were in the community and the efficacy of the various solutions named by the children. The key was to identify common themes the children articulated with evidence-based solutions for excluding or killing the bugs. Following the initial drafting of the song, which at that point contained three verses, the team sought feedback from SNEM, the agency responsible for eliminating triatomine infestation. SNEM requested an additional verse that would highlight and increase acceptability of SNEM's efforts, and the team added it. The added verse was brought back to the children, who did not have any objections to its addition.

The song was brought back to the community in July 2010. Children of Guara community performed the song at the school, and the children were encouraged to bring it home and teach it to other members of the family. Because the song was deployed along with other strategies—including classroom education, media efforts, public health education, community theater, graffiti, and more—it is not possible to assess the impact of the song on children's knowledge, attitude or practices. It is possible, however, to examine the messages themselves and identify promising opportunities for the community.

ANALYSIS OF THE SONG

The song generated in coordination with the children is comprised of four stanzas (see **Appendix A**). The first three stanzas indicate some of the household management behaviors that the children identified as common in the communities and that raise the risk of being bitten by a tritominae bug. Each of these stanzas follows a pattern. First, the presence of the bug is identified ("In my house there is a Chinchorro," "… are two chinchorros," "… are three chinchorros"), and the number of insects found in the home grows larger each time. This move not only identifies the insect as common and present in many homes through the communities, it also makes the insect identifiable by its common name. Rather than naming the specific species of bug that might be found, the children use the local term "chinchorro." After identifying the insect's presence, the next line of each stanza indicates that the insect is one that bites, that the bug is one "who wants to bite me," "to sting you," and "to follow me." The presentation of the insect as one that bites reflects the transmission of disease via the triatomine bug; to contract Chagas' disease, the insect bites to feed and defecates on the host at the same time, and when the host scratches the bite, she or he rubs the feces into her skin and begins the infection cycle anew. The bugs are not passive feeders that bite only out of opportunity; they will emerge from hiding places at night and "follow" their hosts into bed for feeding. Although Chagas is pernicious, contracting it generally requires repeated exposure to the triatomine bite and the parasite contained within its feces. The children recognize this when the bite is repeated with "me, me, me" and "you, you, you" in the third line of each stanza. The children, then, create additional perceptions of greater susceptibility to contracting Chagas' disease because the risk of exposure is repeated.

The susceptibility comes not only from the bite, but from behaviors in the household that create a greater likelihood of triatomine infestation. In the first stanza, the children say a single chinchorro is present "because my mommy has not swept." In the second stanza, two chinchorros are present "because your mommy has not set up the screens." And, in the third stanza, three bugs are in a chicken nest and they were removed when "my mommy moved the nest." Importantly, each behavior is one that must be repeated for it to be effective. This is indicated in the "so, and so, and so" of the first two stanzas where the children also make sweeping motions and pretend to erect netting, respectively, and the "there, there, there" of the third where the children also make pointing motions to show the chicken nest should be moved far away). Each of these behaviors affect the likelihood of infestations; they also require some knowledge of local strategies for insect control. Sweeping the home removes household debris and makes it easier to see signs of triatomine infestation, such as their droppings or carcasses. In addition, the brooms for sweeping in Calvas County are often made from local bushes that have a large amount of acid in their stems (Nieto-Sanchez et al., 2015). Thus, in addition to mechanically destroying nests by sweeping, the acid in the broom can work as a natural insecticide that may prevent reinfestation. Putting up screens may prevent problems of triatomine infestation as well. Although the words did not specify whether the screens represent bug nets erected over the individual bed or screens on windows and doorways into the home, the actions performed as part of the song mime erecting bug nets. Bug nets placed over the individual bed can prevent the transmission of Chagas because the bugs, which generally live in cracks in the home wall or behind picture frames and similar hiding places, cannot get to the body to bite it. If a person hears only the words, an alternative interpretation of placing window screens is also efficacious. Window screens also limit introduction of the insect into the home, as they provide a physical barrier to entry. Whereas, sweeping can remove nests after infestation, screening can prevent the establishment of nest or prevent the bugs from feeding should infestation have already occurred. Finally, even with screening, if an existing chicken nest containing triatomines is not moved outside the home or away from the walls of the home, infestation can occur. It is important then to move nests when one is collecting eggs or raising fighting birds away from the peridomicile and certainly not into the domicile. All three of these strategies are simple behaviors to adopt: sweeping, setting up screens or netting, and moving chicken nests containing chinchorros can easily be performed. It is also important to note the agent to whose this responsibility is assigned: to mommy. Prevention of Chagas becomes a feminine act, specifically a maternal one. Although men (and elders and children) are certainly capable of picking up a broom, the children articulate social norms that make household maintenance the responsibility of women.

Taken collectively, the first three stanzas, first, highlight the presence of infestation, then, indicate the general problem of transmission as well as the individual child's susceptibility to transmission, to locate infestation as a common problem (for me and you), and, finally, indicate the act of that can be performed to lessen infestation as well as its repeatability. The children's stanzas reflect concepts common in health communication theories for promoting behavioral change. The presence of the bug reflects awareness, the representation of transmission reflects perceived susceptibility, and the means of prevention reflect efficacy. The children, then, have identified important facets of promoting health behavior change in Guara that can be message points for a campaign to spread their message.

This community-centered and community-articulated pathway, however, becomes disrupted in the fourth stanza of the song. In the fourth stanza, we are told about a house in which there are no triatomines. The reason that the fourth house has no bugs is not because of sweeping or netting or individual change; rather; this home is bug-free "because SNEM fumigates here." SNEM, the acronym for the now disbanded Servicio Nacional de Control de Enfermedades Transmitidas por Vectores Artrópodos (National Service for the Control of Arthopod Vectors of Infectious Disease), was a nation-wide agency, not an agency based in Calvas County or the community of Guara. In addition to being geographically distant, the solution they provide is insecticide spraying. Spraying is described as an ongoing act, however it should be noted that insecticide must be repeatedly applied with specialized equipment and is very expensive when compared with the average household income in the community. Because of the change in agent (from mother to outside government workers) and the change in act (from the simple and easily accomplished to the expert and expensive), the efficacy, in both perceived and actual terms, of the strategy for eliminating triatomine bugs changes. Indeed, the focus on spraying likely lessens the self-efficacy of families responding to the song. The target of persuasion and the goal of persuasion also changes. The first three verses implied that the family, specifically, the mother, should change behavior. The final verse indicates that the desired outcome is that "we have understood that the chinchorro is not welcome, neither here, nor there, nor there." This outcome is a change in attitude rather than a change of behavior, the change in attitude occurs among the children themselves rather than in the family unit. In this final stanza, then, confusion is introduced as to who is responsible for preventing infestations, how they prevent infestation, and the role of community members in this prevention.

This change was introduced after the children had generated their topics and the initial parts of the song. Because the larger research project of which this song is a part also included staff of SNEM, when the children's topics were formalized into the song, the SNEM members sought additional inclusion of their efforts into the song. This insistence, in part, allows the song to recognize the important contributions that SNEM and the Ministry of Health have made to prevention of Chagas disease but also, in part, distracts from the voice of the community by displacing their community-based suggestions with solutions offered by the central government.

DISCUSSION AND IMPLICATIONS

The use of the Entertainment Education approach in Guara reveals a potentially powerful way of bringing children into the construction of their own health interventions. This song brings Entertainment Education to the context of neglected tropical diseases. As such, our analysis of the song and its development may provide important insights for other practitioners who wish to incorporate this longstanding and powerful form of intervention in the neglected tropical disease context.

The most important lesson is that, in the novel context of Chagas disease, entertainment education can serve as a powerful intervention. Co-creation of this song allowed members of the community in Guara to promote understanding of effective and efficacious personal strategies to combat the spread of triatomine vectors for Chagas disease. Through their co-participation in writing this song, the children emphasized messages about actions they and their families could take. Efforts in communities like Guara have tended to emphasize vector control through insecticide application (e.g., Samuels et al., 2013), but insecticide-based strategies are limited both by difficulties in complete and proper application and by recolonization of homes after the insecticide wears off. We agree with Grijalva et al. (2011) that the most effective intervention will not be the development of a better insecticide but, rather, changes in household behaviors and practices that will prevent initial colonization of the home. Field workers from SNEM generally recognize that lack of financial resources, personnel and the difficulty access to the households in the communities makes it operationally difficult to provide regular insecticide application in rural areas of Ecuador. Therefore, they welcomed the use of community education and entertainment education to promote community-based disease prevention. However, to our knowledge alternative prevention methods have not been implemented to date. Furthermore, since SNEM was disbanded in 2016, systematic Chagas disease control activities have practically ceased in the country (Dumonteil et al., 2016).

Previous research (e.g., Patterson et al., 2018) has approached communities in Loja province to understand the actions and activities members of the community believe will help reduce the risk of Chagas disease. Because the song developed in cooperation with the children promotes these changes and activities—specifically, regular sweeping, using screens, and moving chicken nests away from the domicile—it may be an effective way to communicate these behavioral changes to other members of the community. Moreover, because the song was developed with the children, it is more likely to use language that the community employs and be more understandable to residents of Guara than messages developed outside of the community. And, because a co-participatory approach draws ideas for messaging and insight into lived conditions in a way that top-down approaches do not, participatory approaches are more likely to be more effective than top-down communication approaches (Singhal and Rattine-Flaherty, 2006). Because the song developed with the children adopts a participatory communication approach, it is likely to empower children and the community of Guara to exert control over a significant health threat (see Singhal, 2001).

These potentials for entertainment education approaches encourage us to understand how people assert control in their local communities. EE approaches encourage us to listen to the community to emphasize local knowledge and norms, but also to understand whether there are harmful norms in the community that provide potential loci for change (Riley et al., 2017). In the song developed here, potential harmful norms might exist concerning perceptions of gender roles. Throughout the verses created by the children, bugs can bite children because of the mother's inaction ("mommy has not swept" and "mommy has not set up the screens") or are protected when "my mommy moved the nest." These verses reflect traditional Ecuadoran assumption that women are responsible for the care of families and upbringing of children while men are able to be less active in parenting. Men are just as capable of sweeping floors, erecting screens, and moving chicken nests as women are, but the children do not make fathers responsible for doing these things. Because the children indicated that mothers were important in the prevention of Chagas disease, future efforts in Guara, or in other communities where this approach is adopted, would benefit from including parents in the co-creation of the Entertainment-Education intervention. This inclusion, particularly of mothers, might allow all key players in the community to be involved in construing the messages. Although there are anthropological and sociological explanations for the emergence of these gender roles, the children's communicative choices reveal an important site of intervention for broader social change and possibilities in rural Ecuador, albeit one that should be revisited in future efforts.

In addition to limitations that come from these gender norms, the song was limited in that it returned to an insecticide-based strategy in the final verse. Over the course of the development of the song, public health experts insisted that we add a line that highlighted the work of their spraying program. To retain the support of the Ministry of Health and other governmental actors, we acquiesced, and this action nay have detracted from a central principle in participatory methods that the voice of the community should be privileged over that of the experts. Because this intervention was, however, a co-participatory design, we partially avoided many of the problems associated with top-down approaches. Entertainment Education approaches were initially theorized as being either top-down or bottom-up (Singhal and Rogers, 2001), and many early studies of EE efforts have sorted themselves into being either national (top-down) or cultural/local (bottom-up) campaigns (see Singhal and Rogers, 2002 for a review). Yet, as Riley et al. (2017) demonstrate, this dichotomization has been shown to be false; when entertainment education has been put into practice over the past two decades, a continuum between a more top-down and a more bottom-up approach has emerged.

Because our project was a true cooperation between our research group, SNEM, and the community, our project sought to incorporate the voices of SNEM members alongside those of the community. The SNEM team is correct that spraying the house does kill most triatomines and can complement well behavioral and home maintenance strategies. However, if insecticides become emphasized as the best or only solutions, SNEM's intervention into the song may limit perceptions of the effectiveness of alternative strategies or promote dependence on external intervention in the community. SNEM's participation in writing the song reveals a tension in how EE approaches are assumed to emphasize local voices but how they must also include national voices to gain funding and support from governmental actors. That is, although we privilege the voice of the community because of our commitment to participatory research and intervention, practical matters of governmental and funding relations for other portions of the project must also be brought into the equation. The co-participatory design of this song reveals that there are opportunities for experts to intervene in ways that both enable and disable community voices, with potentially supportive or unsupportive effects for preventing risk factors for neglected tropical diseases.

DATA AVAILABILITY STATEMENT

All datasets generated for this study are included in the article/supplementary material.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Institutional Review Board, Ohio University, Comité de Ética de la Investigación en Seres Humanos, Pontificia Universidad Católica del Ecuador. Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

MG and EB contributed conceptualization and design of the study and collected primary data. BB organized, wrote the first draft of the manuscript, conducted fieldwork related to the study, and the larger project. MG coordinated community involvement and participation from local institutions. DS wrote sections of the manuscript and performed primary theoretical conceptualization of the study. All authors contributed to manuscript revision, read, and approved the submitted version.

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

APPENDIX

Canción (Song) in Spanish and English.

En mi casa hay un chinchorro,	In my house there is a chinchorro,
Que me quiere picar a mí.	Who wants to bite me.
A mí, a mí, a mí.	Me, me, me.
Porque mi mamita no ha barrido,	Because my mommy has not swept,
Así, así y así.	Like so, so and so.
En tu casa hay dos chinchorros,	In your house there are two chinchorros,
Que te quieren picar a ti,	They want to sting you,
A ti, a ti, a ti.	You, you, you.
Porque tu mamita no ha puesto el toldo,	Because your mommy has not put up the screen,
Así, así y así.	like so, so and so.
En el nido hay tres chinchorros,	In the nest there are three chinchorros,
Que me quieren seguir a mí,	They want to follow me,
A mí, a mí, a mí.	Me, me, me.
Mi mamita movió el nido,	My mommy moved the nest,
Allí, allí, allí.	There, there, there.
En nuestra casa no hay chinchorros,	In our house there are no chinchorros,
Porque SNEM fumigó aquí,	Because SNEM fumigated here,
Aquí, aquí, aquí.	Here, here, here.
Y así hemos comprendido,	And so we have understood,
Que el chinchorro no es bienvenido,	That the chinchorro is not welcome,
Ni aquí, ni allí, ni allí.	Neither here, nor there, nor there.

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"What If I Aint Ate in 2 Days, Why the Hell Would I Want You to Poke Into My Arm": A Critical Cultural Analysis of Testing Makes Us Stronger

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Despite medical advancements, Black gay, bisexual, and other men who have sex with men (BMSM) are the group most disproportionately impacted by HIV in the United States. Recent figures estimate one in two Black MSM will be diagnosed with HIV in their lifetime. From 2011 to 2015, the Center for Disease Control ran Testing Makes Us Stronger, a health communication campaign designed to increase rates of HIV testing in the Black MSM community. Past studies document the campaign's visibility, but fail to explain the continuous rise of HIV transmissions within the Black MSM community. Previous research on Testing Makes Us Stronger analyzes exposure to the campaign, but fails to capture the experiences and opinions of its target audience. Using the Culture-Centered Approach, this study conducted 20 semi-structured phone interviews to unveil how culture and systemic inequities influence rates of HIV transmission in the Black MSM community. Thematic analysis found three key themes: (1) trans invisibility, (2) call for holistic approaches, and (3) importance of local organizations. Findings from the study suggest HIV campaigns would benefit from working in tandem with other organizations designed to combat systemic inequalities.

Keywords: HIV Testing, Center for Disease Control (CDC), Black MSM, disparity, critical, Testing Makes Us Stronger

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INTRODUCTION

As rates of HIV transmission in Black men who have sex with other men continues to rise, health communication campaigns are uniquely suited to raise awareness and prompt behavior change. A plethora of social marketing campaigns, including Testing Makes Us Stronger, have launched, yet, they have had minimal impact on decreasing the number of new HIV positive diagnoses. This study seeks to understand why. First, it will discuss the current literature surrounding HIV in the Black MSM community. Next, it offers an overview of the Culture-Centered Approach (CCA) as well as aspects of social marketing, noting their application to Testing Makes Us Stronger. In order to understand systemic inequities in HIV testing, the study sought the opinions and perceptions of 20 Black MSM working in HIV advocacy. Implications are discussed.

HIV in Black MSM

In the United States, there are more than 1.1 million people aged 13 and older living with Human Immunodeficiency Virus (HIV), including the estimated 162,500 people who are living with HIV, but have yet to be diagnosed (Center For Disease Control, 2019a). Rising awareness, increased rates of testing, and more effective treatments have decreased rates of HIV acquisition for most demographics except one: MSM (Singh et al., 2018). In 2017, gay, bisexual, and other MSM comprised only 2% of the domestic population, yet they represented 70% of all new HIV diagnoses (Center For Disease Control, 2019b).

Black or African-American (hereafter referred to as Black) MSM continue to be disproportionately impacted more than their White counterparts, revealing a health disparity. According to the (Center For Disease Control, 2018), health disparities are "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations" (p. 1). Additionally, health disparities frequently translate to stark differences in the incidence, prevalence, and mortality of a disease (CDC, 2018). Recent (Centers for Disease Control and Prevention, 2019) outline the vast difference in HIV incidence rates for Black MSM compared to White MSM, noting Black MSM, especially between the ages of 13–34, were nearly twice as likely to contract HIV. Next, of the 38,739 new HIV diagnoses in 2017, 10,070, or 37 percent of the diagnoses were among Black MSM (CDC, 2019). Other reports and data continue to shed light on this health disparity. For example, in 2013, the National Minority AIDS Council (NMAC) found between 2006 and 2009, young Black MSM saw a 48 percent spike in new HIV diagnoses; additionally, 2011 marked the first time the number of Black MSM diagnosed with HIV surpassed rates of transmission for White men (National Minority AIDS Council (NMAC), 2013). Most alarming, according to a groundbreaking report released at the 2016 Conference on Retrovirus and Opportunistic Infections (CROI Press Release, 2016), if current HIV diagnoses rates persist, 50 percent, or 1 in 2 Black MSM will be diagnosed with HIV in their lifetime, compared to 1 in 4 Latino MSM and 1 in 11 White MSM.

Several hypotheses have been proposed to explain this sharp increase in rates of HIV transmission. It was once believed Black MSM engaged in more unprotected intercourse compared to other MSM, but multiple studies debunk this myth. Black gay MSM do not engage in higher rates of risky sexual behavior (Clerkin et al., 2010; George et al., 2012; Millett et al., 2012; Sullivan et al., 2015). Instead, research suggests racially homophilious sexual networks are a leading factor (Amirkhanian, 2014; Hernández-Romieu et al., 2015). Newcomb and Mustanski's study (2013) was one of the first to analyze sexual network impact on rates of HIV transmission. Using Hierarchical Linear Modeling, their study found Black MSM reported significantly less unprotected sexual encounters than other groups, but were the most racially homophilous group in terms of sexual partnerships (Newcomb and Mustanski, 2013). Their research indicates Black MSM maintain an impermeable sexual network, as Black MSM engage in sexual intercourse almost exclusively with other Black MSM. Although Black MSM do not engage in unprotected sex more frequently than other groups, their dense sexual networks do contain a higher rate of transmission. In turn, because of their condensed sexual network, when unprotected sex *does* occur, there is a greater likelihood of contracting HIV.

Even when sexual networks are considered, individual behavior, such as condom use, partner selection, and consumption of drugs and alcohol, still do not fully explain Black MSM's high HIV incidence rate (Millett et al., 2012; Sullivan et al., 2015). Disproportionate rates of HIV transmission are most likely also driven by a myriad of systemic inequities and social determinants of health[1]. For example, undiagnosed STIs, access to testing, lack of healthcare, socioeconomic status, low educational attainment, and incarceration exacerbate rates of HIV transmission (Harper et al., 2016). The Black community possesses a higher poverty rate than other racial groups, and this impacts virtually every aspect of HIV care (Gayles et al., 2016). The CDC (2019) notes socioeconomic issues associated with poverty-such as lack of access to high quality health care, housing, and HIV education directly and indirectly increases the risk of HIV transmission for Black MSM compared to White MSM. Socioeconomic disconnection, which occurs when an individual is neither enrolled in school or working, has been found to be significantly and positively associated with one becoming HIV positive; multiple studies indicate Black MSM are significantly more likely to be socioeconomically disconnected than their White counterparts (Mayer et al., 2014; Sullivan et al., 2015; Gayles et al., 2016). The lack of economic connection has proven to increase rates of HIV transmission in a myriad of ways. First, lack of economic opportunity or enrollment in school has been linked to both (1) increased substance use and (2) decreased social support, as one's job/school often provides a communication network (Zaller et al., 2017). Zaller et al. (2017) note many MSM use substances, including methamphetamine, alcohol, and cocaine to not only increase sexual pleasure during intercourse, but also as a coping mechanism to deal with the chronic stress of being economically disenfranchised. Additionally, substance use increases rates of condomless sex and spontaneous intercourse (Zaller et al., 2017). Second, the lack of economic opportunity impacts one's access to HIV related care. The cost of securing testing, purchasing important medications, and staying retained in care is directly linked to one's health insurance, which is often tied to employment (Maulsby et al., 2013). Lastly, limited economic and education opportunities, especially periods of homelessness, have been associated with riskier sexual practices. Individuals living in poverty are more likely to engage in survival sex, a transactional act where one engages in sexual intercourse in exchange for food, money, shelter, and other essentials (Kalichman et al., 2011). Next, geographic region is also an important factor to consider. People living with HIV in rural areas face larger barriers to accessing HIV care and medications as well as greater mortality than individuals who live in urban areas (Quinn et al., 2017). In some Black communities, especially in the rural Deep South, one's desire to get tested is simply not enough as access to a testing center is often hours away, highlighting the importance of consistent public transportation and/or the need for more testing locations (Johnson, 2017). Johnson's study unveils another

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[1] Social Determinants of Health (2019). Available online at: https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health (accessed December 11, 2019).

critical layer related to this disparity; structural inequities are often compounded by cultural influences. For example, HIV related stigma is particularly salient in the Deep South, even within the medical community (Stringer et al., 2015). Of the 777 healthcare workers in the Deep South who were surveyed, 93% reported at least one stigmatizing attitude or negative belief toward HIV (Stringer et al., 2015). Analyzed together, these studies suggest not only is it difficult for one to even access a doctor, but, once they enter the physician's room, patients are also forced to combat stigma. Additionally, despite increased knowledge and awareness, religious based stigma in the Black community still influences all aspects of the HIV care continuum (HIV.gov, 2018), ranging from testing to viral suppression (Jeffries et al., 2015). The Black community has steadfast ties to religious doctrine as religion has been a critical factor in helping the community establish hope. The role of religion played an integral part in surviving slavery and enduring racial violence during the Civil Rights movement (Nelson et al., 2016). Unfortunately, these strong religious ties are often weaponized and messages of homophobia are launched at Black MSM, increasing stigma (Nelson et al., 2016). Goffman (1974) defined stigma as a "profoundly discreditable attribute of a person or group that devalues their position in society." Moreover, many Black MSM are "triply cursed," facing racism, homophobia, and HIV related stigma (Arnold et al., 2014). Understanding the systemic inequities as well as cultural and social factors that put Black MSM at higher risk for acquiring HIV is critical to mitigating the epidemic.

Culture Centered Approach to Health Communication

The culture-centered approach (CCA) contends structural inequalities are intertwined with communicative and health inequities (Dutta, 2018). Therefore, if one desires to mitigate a health disparity, they must first address systemic inequities. CCA contends communication exists at the intersection of culture, structure and agency (Dutta, 2008). First, according to Dutta (2018) culture "reflects the shared values, practices, and meanings that are negotiated in communities" (p. 241). Culture refers to how communities make meanings. For example, as mentioned above, religious based stigma is a cultural component impacting HIV testing in Black MSM. Second, structure refers to systems in place that increase or decrease resources, rules, and assumptions within a community (Dutta, 2018). Third, agency refers to the degree of which an individual and/or community can enact daily choices while interacting with structures. Dutta (2018) writes, "whereas agency is communicatively expressed, the process of communication draws upon cultural meanings, and is located in its relationship to structures" (p. 241). CCA cautious against top down health communication campaigns, instead, researchers are obligated to elicit community involvement and input. Through dialogue, knowledge is co-created in community spaces opposed to isolated in the Ivory Tower or board room. Moreover, Dutta (2018) argues CCA is more than formative research that can be used to guide message construction, proper use of CCA shifts decision-making possibilities to the hands of the community. CCA can, and should be used in every step of social marketing campaigns, from message construction to campaign evaluation and processing feedback. Under this framework, this study reached out to community members to (1) evaluate how a HIV social marketing campaign targeting Black MSM was implemented and (2) community perceptions of the campaign.

Health Communication and Social Marketing

Health communication campaigns are frequently employed to raise awareness and promote healthy behavior change (Boudewyns et al., 2018). Kreps (2015) notes the effectiveness of health communication campaigns is influenced by a myriad of factors including: audience perceptions of campaign's desired behavior, message design/strategy, and identifying the appropriate communication channels. According to Kreps (2015), tailored message strategies identify key individual and community factors that drive health-promotion materials. As health communication campaigns have become more popular, more attention has been given to the importance of audience analysis/segmentation and community involvement (Kreps, 2015). When health communication campaigns are specifically tailored, the target audience is more likely to perceive the information as personally relevant, and therefore, the campaign is more likely to be cognitively processed, and ultimately, will have a higher likelihood of changing behavior (Noar et al., 2010).

It is important to note the distinction between health marketing and health communication. According to the (Center For Disease Control, 2020), health marketing is a multidisciplinary area of public health that draws on marketing, communication, and public health practices to inform the public on health messages, health needs, and methods of promotion. Health communication campaigns are undoubtedly a lynchpin of health marketing, but the study of health communication can also be studied through an interpersonal, organizational, and/or pop culture lens etc. Health campaigns often utilize traditional marketing techniques to prompt individuals to adapt their behavior, colloquially known as social marketing (Ramirez et al., 2017). The use of social marketing in public health is widespread, tackling issues ranging from smoking to recycling (Farrelly et al., 2009). Farrelly et al. (2009) found the Truth anti-smoking campaign targeted toward sensation seeking teenagers averted half a million teens from smoking. Additionally, the promotion of condom use internationally, especially in Sub-Saharan African countries, is another example of a large scale social marketing success (Grier and Bryant, 2005). Effective social marketing is predicated on implementing the four Ps.

Marketing Mix

Drawing from the field of advertising, health based social marketing campaigns rely on the four Ps: product, price, place, and promotion (Grier and Bryant, 2005). Outlining the tenets of social marketing is critical to understanding the CDC's Testing Makes Us Stronger campaign.

Product

In traditional marketing, the goal is to yield a profit and sell a physical product; however, in social marketing, the goal is to develop and integrate marketing ideas that harness a social good (Lee and Kotler, 2016). Lee and Kotler (2016) identify two different types of products- (1) core product, or the benefits of a behavior and (2) actual product, the desired enacted behavior. For example, a campaign may desire to increase rates of HIV testing in the Black MSM community; in this instance, the actual product (2) would be the physical practice of one completing an HIV test whereas the (1) core product could be various benefits including: peace of mind, increased trust, and physical health. Next, it is important to note promotional materials (billboards, posters, pamphlets, advertisements) are not considered products, instead, they are classified as promotional resources that increase the likelihood of adopting the desired behavior (product).

Price

Price may refer to monetary costs, but it also includes any sacrifices (emotional, psychological, time) one has to make in order to enact a campaign's behavior (Lee and Kotler, 2016). A behavior's "price" should always be analyzed from the consumer's point of view, and typically, consumers only enact a desired behavior if the benefits outweigh the costs (Grier and Bryant, 2005). Proper audience segmentation and formative research is key to understanding the target community's perception of price (Rimal et al., 2009). For example, for some, the risk of being outed, HIV related stigma and other psychological factors may be more important price points than the monetary medical cost of one receiving a HIV screening.

Place

(Lee and Kotler, 2016) note place translates to action outlets, which requires the audience to not only understand where and when a behavior can be enacted, but also where resources and materials for the behavior are located. Grier and Bryant (2005) write, "place includes the actual physical location of outlets, operating hours, site attractiveness, and accessibility" (p. 323). Place *does not* refer to the placement of promotional materials. In the instance of Testing Makes Us Stronger, place refers to the physical locations where one could get tested (clinics, hospitals, community centers, etc).

Promotion

Often the most visible component, Grier and Bryant (2005) note promotion analyzes what increases the likelihood of the audience buying the product. Promotion refers to both (1) the type of messaging used (fear, guilt, shame, hope, etc.), and (2) where the messaging appears. The use of TV/radio advertisements, print media including pamphlets and billboards, t-shirts, special events, celebrity endorsements, and face-to-face influence are all examples of social marketing promotion (Grier and Bryant, 2005). An example of a social marketing campaign, Testing Makes Us Stronger, is analyzed in the forthcoming section.

Testing Makes Us Stronger

Social marketing campaigns designed to combat HIV via increased condom use and testing have significantly impacted behavior change (Habarta et al., 2017; Boudewyns et al., 2018). In April 2009, The White House and CDC launched *Act Against AIDS*, a multi-pronged health communication initiative designed to raise awareness of rising HIV rates. Under this program, in 2011, the CDC introduced Testing Makes Us Stronger (TMUS), a social marketing campaign that encourages HIV testing for Black MSM (Habarta et al., 2017). TMUS was launched in November 2011 and remained active until September 2015. Although national in scope, the campaign was heavily implemented in eight major cities: Atlanta, Baltimore, Chicago, Houston, New Orleans, New York, Oakland and Washington D.C. The campaign's goal was to increase HIV testing among Black MSM from ages 18–44 (Boudewyns et al., 2018). Formative research, also known as a needs assessment, was conducted, and multiple messages strategies were tested (Habarta et al., 2017; Boudewyns et al., 2018). However, there is a dearth research on *who* participated in these pre-tests, *where* the tests were held, and *how* they were conducted. At best, Boudewyns et al. (2018) write, "as campaign messages and concepts were developed, multiple rounds of pre-testing, including both quantitative and qualitative methods were conducted" (p. 866). Using insights from the pre-tests, the campaign relied on a strength/affirmation based approach and positive communal bonds. Campaign messages infused three different concepts: (1) Knowing your status helps us take care of each other, (2) We are standing up against HIV and stigma by getting tested and (3) We are responsible for our bodies and choices (Boudewyns et al., 2018). Promotional materials were designed to reach Black MSM through multiple channels; therefore, in addition to magazines and billboards, TMUS utilized multiple digital avenues, including targeted social media ads via Facebook and Twitter and a dedicated website (Habarta et al., 2017) (**Figure 1**). The national website provided information about HIV prevention, campaign goals, and a search tool for one to find testing sites based on their ZIP code (Habarta et al., 2017). Additionally, campaign presence was increased for community events such as national conferences, Gay Pride parades, and house/ball pageants (Habarta et al., 2017).

To date, two quantitative TMUS evaluations have been conducted using survey data (Habarta et al., 2017; Boudewyns et al., 2018). Both studies found exposure to TMUS increased self-efficacy to get tested, increased intentions to get tested, and more positive behavioral beliefs toward HIV testing (Habarta et al., 2017; Boudewyns et al., 2018). However, the number of individuals living with HIV continues to rise. Clearly, these findings represent a disconnect between increased testing and a decrease in HIV acquisition amongst Black MSM. These studies do not explore the experiences and complexities related to HIV, instead, they classify HIV testing as a band-aid solution to a complex problem embedded in racism, homophobia, and socioeconomic disenfranchisement. I seek to fill the gap in literature by examining various opinions of TMUS, and how it could be improved. Through thematic analysis, I discuss how cultural components and structural inequities were not analyzed before launching the campaign. In other words, this study unpacks the structural inequalities that permeate through current HIV campaigns targeting Black MSM.

FIGURE 1 | Sample TMUS campaign materials [Testing Makes Us Stronger Poster (Digital image), 2011].

Research Questions

Utilizing the findings from the two previous quantitative studies, the following research question is proffered.

RQ1: How did Black MSM think about TMUS?

RQ2: What role did culture play in Black MSMs' perception of TMUS?

METHODS

Gibbs (2018) explains qualitative research can be useful to not only understand how an individual experiences a phenomenon, but also how they "make sense" of the issue at hand. Kreps (2008) furthers, "qualitative inquiry can provide context and information rich data for increasing the validity of health communication research" (p. 8). Finally, qualitative research can be useful when identifying structures that limit health of marginalized groups (Olson et al., 2016). I contend the fight to transform systemic inequalities can only be addressed after (1) the structures have been identified and (2) we understand the community's perception of the phenomenon at hand. Qualitative research allows researchers to better understand culture, a key component of CCA. Similar to Dutta, I argue that culture is not a simple secondary factor when discussing HIV; culture plays a vital role in the rising rates of HIV transmission in the Black MSM community. Previous research on the culture-centered approach explains how culture plays an important role in how individuals view and interact with their healthcare (Dutta, 2008). Research supports the notion that qualitative research yields fruitful data related to HIV prevention (Arnold et al., 2014; Adams et al., 2018). Adams et al. (2018) conducted interviews to better understand barriers to testing for young Black MSM and transwomen; they found fear for violence to be a recurring theme. A study featuring interviews of 31 young Black MSM found that HIV-related stigma and homophobia, within the larger societal context of racism, were related to sexual risk behavior, reluctance to obtain HIV testing or care, lower adherence to treatment medication, and non-disclosure of a positive HIV status to sexual partners (Arnold et al., 2014). The aforementioned study found that interviewees reported HIV-related stigma at the hands of church and family members. Based on the promise of previous studies, this study followed a similar approach, utilizing phenomenological interviews.

Phenomenological Interviews

A phenomenological study "describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon" (Creswell, 2007, p. 57). This approach allows respondents to discuss *their* perception of a phenomenon. In this study, the phenomenon of interest was Testing Makes Us Stronger, a health communication campaign targeting Black MSM. Next, because CCA is framing this study, I wanted to understand how culture influenced the community's perception of the campaign. Data collection in phenomenological studies frequently consists of in depth interviews (Creswell, 2007). Thus, this study depended on in depth interviews of Black MSM employed in community-based organizations involved in HIV advocacy.

Procedure

Recruitment

Approval for the study was obtained from a large institution on the east coast before data collection began. Data were collected over an 8 month period in 2016 to early 2017. To participate in the study, individuals had to self-identify as Black MSM, and be employed at a community based organization involved in HIV advocacy. Previous research surrounding the general Black MSM community's exposure toward TMUS has already been conducted, but there is a lack of in-depth research surrounding the opinions of individuals who are employed to deliver the services of TMUS. These men employed in community based organizations are (1) often the point of contact for the larger Black MSM community and (2) are often evaluated and funded based on their implementation of national initiatives; therefore, this study sought out their voices and perceptions of the campaign.

Respondents were recruited by snowball and purposeful sampling. First, a formal announcement was made at two conferences, the United States Conference on AIDS (USCA) and National African American MSM Leadership Conference (NAESM). Next, a solicitation message was posted on various social media pages, including the study's principal investigator. Third, respondents were recruited directly by using the contact e-mail located on organizations' web page. Finally, individuals completing the interview were asked to send information to colleagues and peers who qualify for the study. All respondents were provided with necessary IRB information. Since all interviews were conducted via telephone, respondents were given the option of providing (1) recorded verbal consent or (2) the ability to be e-mailed a physical consent form that could be signed; all respondents indicated verbal consent was preferable. Interviews only continued once verbal consent was acknowledged. As part of the consent process, respondents were informed that their quotes would be used in a study; all respondents acknowledged this and consented to quotes being used in publication. No compensation was given for participation.

Participants

After verbal consent was given, the study's author conducted semi-structured phone interviews. Twenty-one (21) semi structured phone interviews were conducted, but, due to recording issues, one interview was omitted. Twenty (20) recorded interviews were analyzed. The interviewer used a series of questions, and probed for further clarification when necessary. Sample questions include:

- How long have you been involved in HIV related work?
- Are you aware of Testing Makes Us Stronger Campaign?
- What are some of the campaigns strengths and weaknesses?
- Do you believe the campaign was successful? Why or why not?
- If you could draft your own campaign, what would it include and why?

All respondents identified as cisgender males. Age varied for the respondents, ranging from ages 22–57 years old. In addition, educational attainment ranged from high school diploma to terminal degree (Ph.D.). To ensure confidentiality, all interviews were conducted in a private library room located on a college campus. In order to ensure anonymity, names of individuals, job titles, and specific places of employment were omitted. Pseudonyms were given to each respondent. All of the interviews were recorded using the iPhone application, TapeACallPro. All interviews were transferred to a password protected flash drive within 24 h, and the flash drive is only accessible to the author as it is held in a locked office. All recordings were permanently deleted from the researcher's personal cell phone. All interviews were transcribed within 2 weeks of recording.

Thematic Analysis

According to Moustakas (1995) a researcher ought to read and listen to their transcripts multiple times to familiarize oneself with the data. After this step is complete, the lead researcher is responsible for identifying and extracting key phrases that highlight respondent experiences; these experiences are translated into codes or labels (Moustakas, 1995). Saldaña (2016) writes, "a code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence capturing attribute for a portion of language-based data" (p. 3). Following the work of Saldaña (2016), the study then coded for repeated patterns, until saturation was reached. Saturation occurs when no new information emerges from the coding and no new properties, dimensions, or actions are seen in the data (Saldaña, 2016). After reaching saturation, the researcher used the coded patterns to establish the most prevalent themes. Next, the researcher isolated key quotations that best illustrated the theme, and captured rich description of respondent experiences. Although the researcher was the sole coder, steps were taken to ensure validity of the data. Throughout the data collection process, the researcher consistently participated in member reflections, a collaborative process where one works with the respondents in the study to ensure transparency and data authenticity. Tracy (2010) writes, "member reflections" allow for sharing and dialoguing with participants, providing opportunities for questions, critique, feedback, affirmation, and even collaboration (p. 844). This study utilized member checks, a type of member reflection, that prompts researchers to take findings back to participants to verify the truth and accuracy of the researcher's interpretation (Tracy, 2010).

FINDINGS

Thematic analysis yielded three key themes: (1) trans invisibility, (2) call for more holistic approaches, and (3) necessity of local organizations.

Trans Invisibility

First, despite the study intending to focus exclusively on Black MSM, several respondents indicated that their community based organization not only serves Black MSM, but transwomen as well.

Joshua, New Orleans

> *My organization primarily deals with Black gay men, but I see quite a few transwomen as well.* (responding to probing question) *My best guess is that they have nowhere else to go. It's really bad down here in the South. Homophobia is bad, but transphobia is worse. I want them to know that this will always be their safe space. So many of them are murdered. . . .in cold blood (pause) So I want them to know. . . .this isn't just a gay space. This is your place too.*

This notion of the organization being a safe space for transwomen was reiterated by multiple respondents.

Robert, Indianapolis

> *I've seen more and more transwomen come through the doors. They are our sisters in the fight. And to be honest, transwomen are the most resilient people I know. The amount of shit they face. . . .I can't imagine. The average life expectancy of a transwoman is something like 35 years old. Imagine that? Imagine thinking you're only going to live for 35 years. We should do more for them. We wouldn't be here if it weren't for them. They have, and will always be a part of this community. As long as I'm here, this door will always be open for transwomen.*

Robert's comments highlight the communal aspect of the Black MSM and transcommunity, a component TMUS relied on. Yet, this finding highlights a disconnect between TMUS and Black MSM, its target population. One of the core components of TMUS was the importance of strong communal bonds, but these quotations support the notion that these bonds not only exist within Black MSM, but Black transwomen as well. Unfortunately, TMUS falsely conflated target population and community. Black MSM consider Black transwomen to be vital parts of their larger community, but TMUS failed to have a component aimed at Black transwomen. Similar to the rates of HIV in the Black MSM community, Black transwomen experience HIV transmission at a larger rate as well. Although only 14% of transgender women in the US are HIV positive, an estimated 44% of Black transgender women have HIV (Center For Disease Control, 2019b). Many of the respondents, like Robert, voiced frustration with these figures, imploring organizations and campaigns to "do more." This idea of leaving transwomen behind and rendering them silent was pervasive in the data. Some argued that the local paradigm of community based organizations systematically silences the voices and needs of transgender women. Responses from the interviewees indicate they believe current HIV focused health communication campaigns fail to include Black transwoman, one of the queer communities most marginalized populations.

Miguel, Miami

> *So I know this interview is about a specific campaign, but I want to make something clear. We have it bad, but our trans sisters got it much worse. No matter how bad I think Testing Makes Us Stronger is. . . ..at least I saw someone who looked like me. Trans women are left out to dry, even by organizations dedicated to Black gay men. And I think that's so messed up. If they can't come here, where can they go?*

Miguel's comments were reinforced by others, who pointed out that trans women have been largely ignored. Some even pointed out that their organization fails to hire Black transwomen, an example of systemic oppression in the form of limited economic opportunities.

Derek, San Francisco

> *In the same way a bullet has no name to it, HIV has no name to it. It can and does impact anyone. We lack the inclusion of transgender women on two fronts. One. . . transwomen of color, particularly Black and Latina need to be employed by these CBOS. . . mine included. No shade. I've tried to bring it up, but I'm always shot down. Two. . . .women come in to my office all the time and I feel bad because I cannot answer their questions. I have noticed we don't include them, it is all about inclusion. Transgender women are individuals who have been left out. I think we need to include them and hear what they have to say. Build some awareness of their issues. It's not the same as my issues as a gay man.*

George, Atlanta

> *We have to get people who don't necessarily identify as gay. Trans women are not gay men. There is a heavy loss when looking at the trans community. I think we need more focus on how we speak to trans women, more research. Those that don't identify as gay but seek out as same sex. There hasn't been any focus on trans women at all. Testing Makes Us Stronger did nothing to change it.*

This analysis reveals that respondents believed there were larger issues at hand than a single campaign, instead, they contend we should be focused on uplifting the most disenfranchised individuals in the queer community. Second, it unveils various systemic barriers at play to transwomen receiving care related to HIV. This will be later explored in the discussion section. To this date, there has yet to be a HIV social marketing campaign targeting transwomen of color.

Holistic Approaches

One of the most prevalent, and perhaps, provocative findings was the call for programs to have a more holistic approach. Several respondents indicated that current national campaigns operate in a utopia, meaning they are predicated on the belief that awareness yields more testing and that testing leads to more care. However, one respondent, Daryl, stated, "this belief is offensive and shows how much they don't know. There is real trauma that can come with a positive diagnosis." There were several calls to address the more systemic issues that exacerbate the epidemic ranging from an overhaul of sex education to addressing homelessness.

Travis, Little Rock

> *Speaking directly to the type of services received. In my opinion, and I know I am young but I am HIV positive so I know what it is like. Every single clinic needs holistic approaches. Food bank, therapists on site. Testing Makes Us Stronger wasn't bad, but it didn't address the larger issues. Poverty, education, jobs. We can't ignore these issues. If we forget about my mental health. . . .what if I'm already depressed from being gay. Me testing positive could trigger a suicide attempt. What if I aint ate in two days. . . ...why the hell would I want you to poke into my arm, I don't wanna do that. If I'm worried about where Imma sleep or how Im gonna afford medicine. . . .I don't care about getting tested. I am not gonna*

> *come to my appointment to get poked with needles. Or I can't think because I'm too depressed cause my family hates me and I don't have a job. Why would I worry about an appointment? The answer is I wouldn't. I wouldn't show up to the appointment.*

Comments like Travis's allude to the power of systems, a tenet of CCA. Additionally, following CCA, the quotation above reveals how systems interact with one's agency. In the example articulated above, the lack of economic opportunity and dearth of mental health services are systemic barriers to one getting tested (agency).

Mike, New York City

> *I think organizations need to move away and I don't think organizations can do this alone. But we need to move away from the idea that testing is the end answer. Testing Makes Us Stronger assumes testing is the answer to decreasing HIV. Well....guess what sis? It's not!(laughter) We need HIV specific services to address issues we already know place someone at risk. Homelessness, survival sex, depression, access, so on so forth. That comes first, then we can talk about HIV. Sometimes I think people think that being Black and gay means HIV is the first thing on your mind, that isn't true. We have tons of other things to worry about. We are still people. Even with Testing Makes Us Stronger.....ok so let's say I wanna get tested. Where do I go? How can I get there? Does it cost? These are things campaigns need to think about.*

Again, similar to Travis, Mike explores cultural and systemic inequities that exacerbate the epidemic. In addition to this, Mike's comment is important as he explicitly states "testing is not the answer to decreasing HIV." Additionally, Mike's comment explores the connection between place, where the desired action can take place and systemic barriers. Simply put, TMUS assumed the *desire* to get tested was the barrier, but this analysis suggests multiple systemic factors are at play. This notion of testing being the beginning, not the end, of combatting HIV is also echoed in the quotation below.

Scottie, Los Angeles

> *We are not going to test our way out of this epidemic* (responding to probing question). *Ummm.. a lot of it will have to deal with addressing those very real structural social issues that Black gay men are experiencing. We don't even think about the fact that so many young Black gay men were never taught about HIV and condoms in school. Let alone gay hookups. They don't learn that. Often times national campaigns don't get to the heart of these issues. I look at HIV funding as a sandwich. The majority of the funding, the biggest piece, I guess the bread is in research and in service delivery. Treatment for folks that are positive and research to improve existing treatment regimens or create new ones. Almost nothing is dedicated to advocacy for public policy that can do some real help for the community. Sometimes, I wanna shake people and say testing is one part of the continuum. It's a piece of the pie, not the whole pie.*

Darrius, Washington DC

> *Testing Makes Us Stronger is coo, but....... (pause) I really don't want to knock the campaign because it tried. It was one of the first times there was a campaign for us. But man... I don't know. (pause) Ok let me put it to you like this. I get tested. Bam, Im positive. Now what? What if I don't got insurance? That's what the campaign misses. I can be positive and never go back to a doctor. I can be positive and go to the doctor once. Get pills and take 'em and think im coo. I can be positive and achieve viral suppression, and stop going. Not knowing that I gotta keep taking the meds. Man, I've had clients who stopped taking their medicine because they were undetectable. They go back to doctor and realize their T cells are low, low, low. Its level to it.*

Scottie's comments, paired with the others, highlight a prominent problem with the goal of TMUS; all respondents indicated testing alone is not enough. Scottie mentioned to "the continuum," which refers to the HIV care continuum. According to the (Center For Disease Control, 2019b), the HIV care continuum consists of five steps: (1) testing and diagnosis, (2) linkage to care, (3) retained in care, (4) prescribed antiretroviral therapy and (5) viral suppression-"undetectable." The comments above argue that TMUS assumes the most important stage is diagnosis, but they refute that claim. According to the analysis, campaigns ought to address various aspects of the HIV care continuum. It is important to acknowledge the structural barriers which influence access to care.

Local Organizations

Lastly, respondents revealed the importance of local, community based organizations. Several individuals contended local organizations are more in touch with the needs of the community. Dutta (2018) would argue local organizations are more in tune with cultural norms, and therefore, better equipped to aid their communities. Local organizations are key players in the process of co-creating knowledge with their clients.

Chris, Atlanta

> *We received money from CDC for Testing Makes Us Stronger, and it got a bit tense.* (responding to probing question) *Because they would come down and say "why aren't rates going down?" Sounded very accusatory. Like we aren't doing enough or aren't trying. I had to tell them, look. You don't get it. They only get statistics, but we deal with people. I don't think statistics can gather everything. People come with stories and backgrounds. That matters. Only local organizations can really reach those who need it most. If a old white man walk in here asking to test folks, there aint no way my clients would trust him.*

The idea of community based organizations being the lynchpin of HIV advocacy was reinforced by others as well.

Julian, Birmingham

> *(referring to TMUS) I wish they would have talked to local organizations more. They gave us some pamphlets and new testing training and left it at that.* (responding to probing question) *Of course we have to reach out to CBOS. Why? Because they are community based organizations. CDC....the CDC is like the parent if I may. They basically say we are going to extend some opportunities to you. These are the things that you can do and the resources we are going to give you to draw in these people. They give it to CBOS and CBOs are the heart. It is their job to hit*

> *the ground and get people. Let people know…come to my facility. Where people look like you. We got you. I've been in their shoes so if they are reluctant, I get it. I just stay patient.*

In addition to the call for community-based organizations, several respondents indicated that these organizations need to employ more Black MSM, particularly, HIV+ Black MSM, stating that representation is important. In short, they argue that because Black MSM who are HIV+ operate in such a unique social location due to being "triply cursed," representation and visibility is key to decreasing the number of Black MSM diagnosed with HIV. The act of hiring Black HIV+ MSM is a way to combat systemic oppression within the community.

Travis, Little Rock

> *You know what's wild? The CDC gave all of that money to Testing Makes Us Stronger, but did nothing to make sure more of us were hired to do the testing. So they put us up on some posters and internet, but when people go to get tested……we aint nowhere to be seen. It can be hard to approach people that aren't like you. I know some Black guys are homophobic so I desperately need for a community organization to make me feel safe and secure. Even sometimes with Black gay men….I feel like when I say I am HIV positive, they judge me. Being positive and negative are two very different experiences. We need more HIV positive people in organizations because they know what we need.*

DISCUSSION

Although other studies have analyzed exposure to Testing Makes Us Stronger, this was the first to analyze the campaign through a critical cultural approach, yielding several implications. First, respondents were aware of the systemic barriers that influence increased rates of HIV transmission in the Black MSM community. Drawing on their own experiences, they argued issues like homelessness and economic opportunities are not mere by products of HIV, instead, they are critical factors increasing rates of HIV; therefore, when discussing HIV, social marketing campaigns alone are simply not enough. Combatting rates of HIV transmission is undoubtedly a public health issue, but it is one that must be addressed from multiple angles including public policy, education, mental health, and housing. The spread of HIV in the Black MSM community is one rooted in social determinants of health. The Office of Disease Prevention and Health Promotion (ODPHP) recognizes the impact of social determinants on health outcomes. According to the ODPHP's Healthy People 2020 campaign, social determinants of health are "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affects wide range of health, functioning, and quality-of-life outcomes and risks [The Office Of Disease Prevention and Health Promotion (ODPHP), 2019, p. 1]. Examples of social determinants echoed by respondents include: availability of housing, access to quality education, affordable health care, and food insecurity. Following CCA would allow for researchers to identify the myriad of systemic factors that influence one's risk of contracting HIV.

Second, analysis shows the importance of applying CCA to social marketing campaigns. For example, social marketing contends place, or a location where a desired behavior is important; applying CCA to campaigns forces researchers to evaluate *if* the place is accessible to the target population. Additionally, price, or the sacrifices one makes to engage in behavior, is undoubtedly culturally constructed; cultural norms of testing, HIV status, homophobia, and stigma are all incredibly important to the Black MSM community (Arnold et al., 2014). Third, analysis reveals TMUS focused on the wrong "product." The campaign was framed around testing, but analysis revealed that for our respondents, testing alone is not how we are going to mitigate HIV in the Black MSM community. As one respondent indicated, one could test positive for HIV, and still, have no clear trajectory or plan for accessing and affording care. Worse, a positive diagnosis in conjunction with severe economic disenfranchisement may lead one to adopting a fatalistic mentality. The campaign seemed to assume the target population had no *desire* to get tested, but findings from this study suggest otherwise. High locus of control or increased perceptions of self-efficacy are rendered obsolete if one (1) does now know where to get tested, (2) can't afford testing, and (3) has no ability to get to the testing location. Additionally, accepting the premise of testing being the foundation of a HIV mitigation strategy also assumes doctors and healthcare workers are willing to overcome their HIV related stigma, yet, studies reveal stigma runs rampant. Social marketing campaigns must focus on the various stages of the HIV care continuum; it is imperative that researchers and scholars do not view testing in a vacuum. As a respondent stated, it is a piece of the pie, not the entire pie. I argue these multiple campaigns can and should be run concurrently. For example, TMUS could have simultaneously be run with an Undetectable=Untransmittable campaign, targeting individuals at various stages of the HIV care continuum. Fourth, as the last theme revealed, many respondents felt silenced, scrutinized, and shut down by national organizations. In addition to this, the lack of trans inclusion in the TMUS highlighted a disconnect between the campaign goal and community perceptions, highlighting the importance of community based participatory research. Previous research from Kreps (2015) and Noar et al. (2010) has already established the importance of proper message tailoring and audience segmentation, and community based participatory research reinforces this importance. Similar to CCA, community based participatory research avoids a top down approach to health campaigns, instead, it invites community members, organizational representatives, and academic researchers to contribute and comment on all phases of the research process (Rhodes et al., 2010). As articulated above, CCA encourages a paradigm shift, where agency should exist within the community, not just researchers. Respondents in this study would agree; according to the respondents, TMUS would have been more effective if the voice of the community would have been allowed to permeate through the entire process, ranging from defining the problem to implementation of campaign materials. Instead, they felt as if they were told what they could do as well as when and how they could do it; simply put, their agency was taken away.

Local community organizations ought to always have a seat at the table.

LIMITATIONS

This study possesses various limitations. First, it used snowball and purposive sampling, relying on individuals to reach out to their individual networks. This type of sampling could skew results by relying on people who are already well-connected and knowledgeable. For instance, each individual interviewed is employed and experienced in HIV advocacy, therefore, their critique and read of the campaign may be different than someone who is not involved in health promotion. Also, the author made an announcement at several national conferences related to HIV, but many organizations do not have funding to send individuals to such conferences. Next, while there were multiple respondents from the Deep South, none of the interviewees reported living in rural communities. This is an area ripe for future research, especially considering HIV continues to rise in the rural South. Second, despite conducting member checks, the analysis of the data relied on one coder, but different researchers may code interviews in vastly different ways (Saldaña, 2016). Lastly, as with any qualitative study utilizing interviews, the findings are not designed to be generalized, instead, they only represent the opinions and perceptions of the 20 respondents.

CONCLUSION

Rates of HIV transmission continue to rise in the Black MSM community. Health campaigns, such as Testing Makes Us Stronger, have been implemented, but have had limited success. Quantitative studies have illustrated the promise of the campaign's exposure, but there is a lack of research surrounding community perceptions and understandings of the campaign.

Qualitative interviews and thematic analysis revealed TMUS not only failed to account for various structural barriers, including homelessness, poverty and education, but it also ignored the voices of community members and local organizations. Future health communication campaigns should utilize CCA as a lens to unpack how culture, systems, and agency influence one's access to HIV care across the continuum.

DATA AVAILABILITY STATEMENT

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by IRB George Mason University. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

All of the ideas and writing presented were conducted solely by the corresponding author.

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The Language of Women's Pain: Ideology and Critical Cultural Competencies in Pain Literacy

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This manuscript is concerned with a key tension in health communication: How women's pain is rhetorically constructed and culturally consumed. To date, there has been much research devoted to communicating the language of pain, rather, pain's inexpressibility (Scarry, 1985), as well as the construction of health narratives from private pain into public action (Kimball, 2000). Building on that literature, we make a rhetorical turn, and argue for a more critical rhetorical approach to pain literacy. To that end, the primary goal of this essay is to explore the rhetorical nuances and ideological limitations in pain literacy, from the point of when pain is expressed to how that expression is perceived. Through a critical cultural lens, we critique dominant narratives of pain, and argue for an intersectional heuristic of rhetorical care that promotes cultural competency and awareness to bridge gaps in the expression and perception of pain literacy.

Keywords: pain literacy, rhetorical care, health rhetoric, race, cultural competencies

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INTRODUCTION

In January 2018, Serena Williams, arguably the greatest and most recognizable tennis player in the world, especially in women's tennis, shared with *Vogue Magazine* (Haskel, 2018), and in an HBO (HBO, 2018) documentary, that she nearly died, twice, after giving birth to her daughter. She experienced an all too familiar statistic for Black women post childbirth (CDC, Surveillance), a pulmonary embolism, or blood clot in the lungs. Although the threat of the condition is horrifying enough, what is most telling for the purposes of this essay, was that one of the most famous women in the world expressed pain and fear of early clotting symptoms post-delivery, yet, the delay in her care was almost fatal. Serena Williams says she pleaded with doctors for hours to address her pain, because as no stranger to blood clots, and understanding the severity and necessary immediate attention, she knew she had to move fast, especially if she were ever to play tennis again. As a world-class athlete, she knows her body, and knows how to communicate for her needs. She knew exactly what tests to request, exactly the progression from diagnosis to danger zone, yet, in her own words "Doctors would not listen to me," and later, in an interview with BBC (Fuller, 2018) "Doctors aren't listening to us [Black women]."

This pop cultural anecdote of Serena Williams is only one of many recent mediated examples that sheds light on a larger phenomenon: a mystification of women's pain, which leads not only to a lack of agency for women in pain, but also an articulation gap between pain expression and pain perception. Such a communication gap has led to misdiagnoses and delayed treatment for women whose expressions of pain are misunderstood or overlooked (Hoffmann and Tarzian, 2001). As a launching point for discerning pain expression and pain perception, we define pain literacy as it is rooted in Scarry's (1985) framework, where pain expression is the tension between the pain humans feel, then the articulation of that feeling to an audience; pain perception is how the receiver of that information, presumably a health care provider, responds to that communicative act. Scarry argues that this continuum from expression to perception is one of the most difficult semiotic undertakings of human language. While there are many limitations in pain articulation, we argue that one contributing factor to this gap is ideology, which is to say, a lack of attention to negotiating power competencies around the critical cultural identifications of race and gender. When we say ideology, we are invested in how marginalized voices challenge status quo normative narratives of a power structure. We situate and define normative health communication literature as a source driven by white-cis-heteromasculine perspectives, that are inherently exclusionary of marginalized populations outside of that norm. For the purposes of our essay, we are concerned specifically with the rhetoric and language of Black women's maternal health. Thus, when we use the term marginalization moving forward, we mean the exclusion of Black women's voices in healthcare narratives.

For women, specifically Black women, attempts to communicate pain during initial interactions with care providers can be met with skepticism (Weir et al., 1996) or with a misbelief that pain is caused by emotional factors rather than biological ones (Elderkin-Thompson and Waitzkin, 1999). We contend that beyond emotional factors and a lack of patient trust or empathy, there is another factor contributing to care gaps for women: Ideological incompetence and dismissal—informed by racial bias (Chuck, 2018), whether implicit or overt.

We started with a cultural anecdote because we argue for a cultural shift; rather, how pain is rhetorically constructed for Black women. For the purposes and scope of this manuscript, we wanted to look specifically at language gaps in care for Black women because of the expressed advocacy from groups like *Black Mamas Matter* and growing communication literature addressing health campaigns combatting Black maternal mortality. More directly, this has been a health issue since the infancy of health communication, but is growing momentum in communities that want to tackle bias and racial gaps in the field. Building on the literature of pain expression (Scarry, 1985; Kimball, 2000; Bustan, 2016), we argue that a key factor in pain literacy goes beyond gaps in epistemology, or the language and vocabulary of pain, but is also an ideological endeavor, where women's pain narratives are disciplined or managed through normative health narratives. In other words, to address Black women's experiences with pain in a more meaningful way, we have to not only consider the language used to describe pain, but the structures in place that prevent the pain experiences of this marginalized group from being taken seriously. But first, we need to define two key terms used throughout this manuscript; first, ideology, which we see as power, who has it—who doesn't—and how it is used to further marginalize communities of historical oppression. The second term, "critical cultural competencies," is a sub-field in rhetorical studies within communication studies literature, where "cultural competency" is a term often used to define and interrogate conditions outside or opposed to normative rhetorics (Crenshaw, 1989; Berlant and Warner, 2002). In the critical rhetorical community, difference is understood as rhetorical motivation through experience, agency, and autonomy that serves to challenge normative social, cultural, and political discourses.

As a launching point, we will first situate and define pain beyond embodiment, which is to say, pain as it relates to power and policy through an intersectional and critical race lens (Crenshaw, 1989). Then, employing rhetorical criticism as a theoretical and methodological lens (Campbell, 1963; Campbell et al., 2014), we advance "rhetorical care" as a speculative lens for closing ideological gaps in pain literacy. We then turn to congressional testimony around House Resolution 1318, a Congressional resolution titled "Preventing Maternal Mortality" in order to interrogate racial indifference. Finally, after unpacking the testimony through a descriptive and rhetorical analysis, we argue for a heuristic shift in pain narratives which breaks from normative discourses of pain that further marginalize women, especially women with racial and ethnic barriers to care.

THE LANGUAGE OF PAIN

Pain literacy, defined as the rhetorical life of pain expression to pain perception, is largely considered an epistemological function, rather how the language and vocabulary of pain are used to express and detect one's discomfort. According to Scarry (1985), there are two categories of pain research, material—read physical—and verbal—the expression of pain. More specifically, Scarry offers five features for the linguistic function of pain expression, including: (a) description of experience from those in pain; (b) individuals speaking for, or with, those in pain; (c) a physician's work, the McGill Pain Questionnaire for example; (d) courtroom language that assesses and establishes damages for those in pain; and finally; (e) literary representations of pain (1985, p. 6–10). Beyond these five criteria, our analysis extends on one additional criterion in pain comprehension: ideology, as it relates to a combination of power, influence, and historical oppression of marginalized groups, in our case, black mothers. The Scarry model shows how most pain assessment, literacy, and perception is epistemological, rather, concerned primarily with forming and creating a language and vocabulary of pain between sender and receiver. However, we know that the construction and application of language does not happen in a vacuum, but is informed by rhetorical and historical situations that allow for context and creation of new opportunities and barriers for articulation.

Critiques of Scarry (Bustan, 2016) take up concerns of epistemological gaps, which are largely linked to the private nature of one's experiential pain, and lack of ability to have that pain expressed or translated the way one intended. Bustan confirms, "pain and suffering are defined, on one hand, as predominantly private experiences, often making people feel lonely and misunderstood by others who cannot feel and therefore grasp what they are going through. On the other hand, these phenomena embody interactions among different modes of subjectivity (self/I-you-him-them), thus defining them as substantially intersubjective" (p. 365). Because causes of pain and experiences with pain can vary widely, it can be difficult for practitioners and loved ones to comprehend fully the scope, severity, and persistence of an individual's pain (Magid, 2000). Further, Magid (2000) defines pain as "a perception communicated through both language and nonverbal behaviors such as tears or agitation. As such, pain is intrinsically subjective and inaccessible" (p. 114). Viewing pain in this way (as a "perception") both validates and challenges an individual's account of the pain experience.

Bustan, in nuancing Scarry's perception and five criteria of expressibility, also calls for addressing gaps in pain literacy, specifically pain as a lived modality, rather "whether pain is visible or obscure, essentially mine or dependent on others, subjective or interpersonal… or continuous swings between the worlds." (p. 365). However, even this perspective is mostly interested in defining, and teasing out, linguistic functions of pain toward the goal and outcome of expressibility. There is an extensive body of work within the field of health communication defining health literacy (Sørensen et al., 2012), establishing best practices for improving health literacy (Batterham et al., 2016), and evaluating outcomes of health literacy-focused interventions (Gazmararian et al., 2010). However, very little has been done to refine the concept of health literacy to capture the nuances of pain literacy; that is, looking at the language used to define and respond to a pain experience while simultaneously considering the larger cultural and social mechanisms in place that quell the voices of marginalized patient groups. As noted above, much of the emphasis in this area has been put on measuring and evaluating expressions of pain; less has been done to examine not only reactions to pain, but the ideological grounds in which those reactions are formed.

With the field's pre-occupation of language deficiencies, admittedly an important site for continued investigation, little agency is given to the rhetorical situation of not only how one feels pain, and expresses it, but importantly, how it is perceived based on assumptions of those in pain. To that end, we add to a criterion that Scarry flirted with, but never specifically took on, which we identify as ideology, rather, how power mechanisms serve to prop-up normative health narratives that often do not serve marginalized communities. Before introducing, and ultimately critiquing, dominant ideologies, we do wish to situate our critical rhetorical perspective in the existing health communication literature, drawing particular attention to existing gendered assumptions in pain literacy.

Although a substantial amount of work has been done looking at descriptions of pain within a clinical, patient-provider context (McDonald et al., 2000; Stanik-Hutt et al., 2001; Daly Quinlan-Colwell, 2009), less has been done to evaluate the language of pain within text-based and media contexts, which is to say, how pain is expressed and ultimately perceived. Understanding how individuals describe their experiences with pain both in and out of a medical setting can be useful for empowering patients and ensuring that pain is managed effectively (Chung and Lui, 2003; Tveiten and Meyer, 2009). Further, identifying differences between responses to pain experienced by men and women, especially women who face racial and ethnic barriers to care, can yield important implications for shifting the narrative of how women are viewed within the healthcare system.

The International Association for the Study of Pain (National Institutes of Health, 2019) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." Pain is the most prevalent reason for seeking medical help, it is a subjective experience, and afflicts more Americans than heart disease, cancer, and diabetes combined (National Center for Complementary Integrative Health, 2019; National Institutes of Health, 2019). The issue of pain management has garnered even more attention in recent years with the opioid epidemic and rise in opioid-related deaths as efforts to provide alternative and less addictive forms of pain medications have increased (McGinley, 2018; Centers for Disease Control Prevention, 2019a). Initiatives like the United States Food and Drug Administration's (FDA) "Voices of the Patient" provide a platform for patients of chronic pain to share their stories and provide input on the challenges associated with finding effective methods of pain management (United States Food Drug Administration, 2019). Efforts such as these are helpful for creating spaces in which members of the public are seen as "experts" because of their own, unique experiences with navigating within the healthcare system in an attempt to find pain relief. However, more work needs to be done to create space and opportunity for marginalized voices to share their experiences of how their embodiments of pain are viewed and reacted to.

With regard to gender differences and biomedical outcomes, women have been less likely to be referred for cardiac catheterization (Schulman et al., 1999), to undergo coronary bypass surgery despite having equal or greater cardiac impairment as men (Steingart et al., 1991), to be sent to sleep laboratories for addressing symptoms associated with sleep apnea (Larsson et al., 2003), and to be referred for treatment of attention-deficit/hyperactivity disorder (ADHD) symptoms by teachers (Sciutto et al., 2004).

While it is true that there are biological differences between males and females that impact the onset and progression of some diseases (Buvinic et al., 2006), life expectancy rates (Murphy et al., 2018), and responses to certain kinds of drugs (Zopf et al., 2009), there is also evidence to suggest that expressions of pain from women are viewed differently which has led to women not being taking as seriously when describing or seeking help for their pain (Hoffmann and Tarzian, 2001), thus receiving an incorrect treatment dose (Weisse et al., 2003).

Perhaps of greater concern, is the notion of diagnostic delays which occur when there is a delay between the onset of symptoms that a patient experiences in a diagnosis (Selvam Paramasivam et al., 2017). From the Serena Williams example that started this essay, and in Kira Johnson's story below, the time from expressed pain to diagnosis is critical, and can be fatal if pain management is not addressed with immediacy. Female patients are more at-risk for experiencing diagnostic delays (and thereby delayed treatment) for multiple cancers including bladder, colorectal, lung, head and neck, gastric, and lymphoma (Din et al., 2015), endometriosis (Husby et al., 2003), and tuberculosis (Karim et al., 2007); even though female patients, on average, make more visits to their primary care physicians than men do (Bertakis et al., 2000). Beyond Scarry's initial five criteria for pain expression, this discrepancy suggests that there are speculative barriers to communication in place that contribute to delayed diagnoses and the enactment of treatment plans. We argue that discrepancy is an ideological limitation.

Additionally, it is important to consider the language used by individuals experiencing pain and how this might shape their perception of reality when it comes to living with pain. Strong et al. (2009) found that women used more graphic language, sensory words (e.g., "throbbing," "sharp," "stabbing"), and similes than men when describing their pain. Women also identified more mental images and used more words in general when describing their pain experiences (Strong et al., 2009). These authors theorize that this may be attributed to differences between men and women in socially and culturally learned responses to pain, such that men are traditionally expected to remain stoic in the face of pain and therefore, possess a smaller lexicon of pain descriptors (LeResche, 2011). To that end, recognizing and challenging the influence of hegemonic narratives in medical and public health spaces can be useful in devising more effective and empowering ways for exploring gaps in the pain literacy literature. Expanding on the gaps in the language of women's expressed pain, and in turn perceived pain in health communication contexts can perhaps offer language functions that do not discipline gender or skew toward dominant hegemonic narratives; thus, offering a more inclusive language model for pain management initiatives.

CULTURAL COMPETENCIES IN HEALTH COMMUNICATION: RACE AND IDEOLOGY

From the literature above, we can see some key take-aways from those addressing gendered gaps from pain expression to pain perception. First, an acquiescence that patients and physicians need to be using similar vocabularies to communicate needs and responses. Second, that the experiential reality of the patient and their expressed pain is perceived as a reflection of that reality. To that end, we argue that an inherent criteria for that reflection goes beyond epistemology, and is indeed ideological, meaning, shaped by rhetorical situations of identity and experience (Crenshaw, 1989) as it is defined and disciplined by dominant health narratives that can't or don't account for power gaps in the research of medical care. A critical cultural lens is necessarily fluid in order to adapt to how history has shaped cultural awareness and competencies of gender, race, class, and sexuality (Berlant and Warner, 2002). Following, we argue that there are ideological gaps in expressibility, inherently because the narrative arcs of pain literacy are not critical—which is to say—dominant health narratives do not engage with the lack of representation of traditionally marginalized communities, and how that perceived reality reinforces status-quo approaches to care. It follows then, that either explicitly or implicitly, health gaps are exacerbated and even deadly because of othering, effectively stripping visibility and agency from marginalized groups. From the earlier examples, would Serena Williams have been treated differently if she were white? We can't know, but the point here is that we can speculate, with a solid foundation in historical discrimination (Roeder, 2019) that race and the lack of articulation about race, is a factor, or should be, in understanding and studying the language of women's pain, how it is initially expressed, then medically perceived and comprehend, and ultimately treated.

Health communication literature continues to grow in studies for critical communities, including addressing transgender gaps in access and visibility (Perez-Brumer et al., 2018), health disparities and discrimination in the LGBT+ community (Harvey and Housel, 2014), and poverty invisibility (Redman, 2010). Critical communities are defined here as counter-publics often pushed to the margins of public sphere and normative comprehension of healthcare, often because marginalized communities are seen as antagonistic to hegemonic status-quo discourses of power. When we say critical agencies, there is a breadth of possibility, and multiple directions the literature could expand; however, for the sake of specificity and a focused scope for this manuscript, our rhetorical analysis looks at an example of pain expression from the ideological lens of race and ethnicity, in the case of Black women and Black maternal mortality post childbirth.

We know that there are material health consequences to patient care rooted in racism and discrimination—from racial disparities in pain prescription delivery (Tamayo-Sarver et al., 2003) to the condition of weathering (Geronimus, 2003) where African Americans experience the literal and structural weight of health conditions brought on by physical and psychological consequences from slavery and centuries of oppression in the United States. With those medical and health communication perspectives in mind, we ground our rhetorical analysis through a critical race lens (Crenshaw, 1989) in order to assess and perhaps intervene in pain literacy gaps tied to race and gender incompetence. To explore and highlight the ideological gaps in pain expression and perception through a lens of critical race studies, first, we need some historical and rhetorical context. Medical and health disparities, and the African American health experience are inextricably linked to American slavery (Barr, 2010). Structural oppressions were perpetuated through government policies and legislation following the Civil War and executed through Jim Crow reconstruction laws. In the medical community, discrimination and marginalization were exacerbated through experiments like sterilization of Black women, eugenics theories, and the Tuskegee syphilis project (Washington, 2006; Barr, 2010). Very few medical schools, hospitals, or care facilities accepted African Americans for formal medical schooling and training, and with the effects of white institutions not accepting Black applicants and the Flexner (1910) closing five of seven Historically Black (HBCU) medical schools, there was little to no access or upward mobility for African American physicians in the late 19th and early 20th centuries. As a consequence, not only was there a lack of representation to build epistemological functions of the African American health experience, but the institutional racism made health disparities inherently political and ideological (Arrington, 2015). This is to say that the inequities, lack of access, and structural oppressions explicitly de-limited health narratives for the African American community, and as a direct result from those material realities, the gaps in contemporary health management are not just linguistic, but cultural gaps in awareness and competencies of communities defined by difference.

Arrington argues (2015), two sources of injury remain intact from the aforementioned historical oppressions; the first, a collective distrust of health professionals in the African American community, which can certainly affect expressions of trauma and pain, and the second, a material and lasting violence committed by the health community, which created a suspicion that health professionals were using medicine to intentionally keep African Americans powerless (p. 5). A key take-away here, in addressing contemporary ideological gaps in pain literacy, is a cultural awareness that the legacy of exclusion and disciplining of the African American health experience silenced agency. To that end, whether implicit or explicit, dominant narratives are formed around in-groups, which subsequently provide for the erasure of experience, identity, and unique challenges of the marginalized out-groups.

So, how do we work to close those ideological gaps in gendered and racial health narratives? The call is fairly specific by Barlow and Dill (2018) who write to "re-imagine" holistic Black women's health through an intersectional feminist lens; their call: "confront the epistemic violence of erasure and silos that minimize the voices, expertise, and ways of knowing of interdisciplinary, transdisciplinary, and anti-disciplinary scholars," (p. 2) and we would add here, health scholars and practitioners. As an operational and speculative lens to address these ideological gaps and lack of cultural competencies, we advance rhetorical care, rather, care as a bridge from private expressions of pain, to how pain is perceived, and managed publicly.

OPERATIONALIZING PAIN LITERACY AS RHETORICAL CARE

Care—as an operational theory—is largely attributed to Carol Gilligan's perspective found in, *In a Different Voice* (1982), and later, expanded into political and social theories by Tronto (1993, 2013) and Fisher and Tronto (1990). For Gilligan, a "different voice" is defined as privileging unique lived experiences of women, because "the way women talk about their lives is of significance, that the language they use and the connections they make reveal the world that they see and in which they act" (p. 2). Gilligan's care work developed out of a curiosity of the disconnection between men's and women's voices when they described, rather expressed, themselves in their own lived experience. Gilligan was writing from a social psychological lens, where in this literature, men's voices were ascribed public embodiment, and women's voices were relegated to a private sphere, and importantly, there was no bridge between the public and private. More than situated in a private sphere, for Gilligan (1982), women's descriptions of their embodiment were not listened to or taken seriously if there was no outcome our materiality realized outside of the private sphere. Gilligan, then, was committed to closing this binary, particularly in reproductive healthcare. More specifically, her concern was how women's voices, when describing their bodies, could be privileged in discourses of maternal health.

Gilligan's work was unapologetically essentialist in nature because it privileged the differences that women experienced biologically and learned culturally. Although inherently exclusionary, so consequently critiqued throughout feminist rhetoric (Tronto, 2013); her framework provides an epistemological lens for privileging and centering the voices of women in health communication. Rather, as she argues, "the difficulty women experience in finding or speaking publicly in their own voices emerges repeatedly in the form of qualification, where a public assessment and private assessment are fundamentally at odds" (Gilligan, 1982, p. 16). That qualification contributes to gendered binaries between private expressions and public perceptions of pain literacy.

Because early feminist interventions of care were embedded and theorized within psychology, care was contextualized as the motivation of the actor being studied (Woman v. Man), and feelings of care were shaped based on experiential understandings. Fisher and Tronto (1990) and Tronto (1994, 2013) brought care into communication and political literature by claiming care was tied not only to the actor, but the action [Act] of women's lives, particularly as that act played out in a public sphere. Introducing a new discourse for discussing gender in a public sphere, Tronto (2013) argues that we must revoke the inherent public/private split of care, specifically as it is positioned and privileged in the private. In an explanation of a public (read policy-governance) and private divide in relationship to care, Fisher and Tronto (1990) argue.

> In this bifurcation, men's motivations lead them to behave purposively in the male sphere, which encompasses public matters, legal rights, paid labor, and formal relations. Women's motivations lead them to care in the female sphere, which encompasses private matters, familial duties, unpaid labor, and personal relationships. Because this bifurcation both stresses women's caring motivations and makes women's caring work relatively invisible, caring remains a mystified and oppressive concept (p. 36).

Many scholarly critiques of Gilligan were concerned that if care was essentialized toward privileging a woman's experience, government policies and legislation would continue to exclude the voices of women. However, what is important, here, is that Gilligan did not just give an epistemological function and method, she turned toward ideological implications in health disparities. Her research expanded on gendered notions of human development through life-cycle theory, meaning how people (for Gilligan, women) voice and shape their experiences. Gilligan traced "moral linguistic conflicts" through three case studies in reproductive healthcare. In the end, she contends that an ethic of care, although it may grow out of victimization or sexism, can be harnessed as empowerment through difference, and used to challenge hegemonic limitations.

Gilligan's perspective was tied to a feminist perspective rooted in the primary assumption that gender matters as a criterion for understanding what voices are being silenced, and what structures are responsible for the silencing. For Gilligan, equality was only attainable if the experiences of women were as privileged [if not more in policy debates like reproductive health] as the masculine experience. To that end, the only way to challenge exclusion, is to privilege the strength of the marginalized identity and voice, because as Gilligan argued, it is through the morality of care (1992) that women have significant advantages and training because of their systemic oppressions, where men do not.

As a launching place from Gilligan's ideological turn of care, we concede here that the personal is political. Fisher and Tronto show that "caring about" is a process in which "we select out and attend to the features of our environment that bear on our survival and well-being" (p. 41). Traditional notions of care, as they are theorized by Gilligan were a relational concept tied to the motivation of the actor. Tronto theorizes care beyond motivation, where the orientation of care is not only relational and tied to motivation of the actor, but also a practice where the act and maintenance of society is, in fact, care work. Rhetorical care, then, is a speculative lens of discovery to interrogate the motivation (actor) and orientation (act) in determining ideological intervention.

To define and operationalize a heuristic of care, we build from Tronto's initial four methodological elements of care work, which were: attentiveness, responsibility, competence, and responsiveness. The four elements advance a prescription where motivational care is a conscious understanding of how care work is communicated through four habits, which for Fisher and Tronto (1990) are defined as: caring about, or noticing the need to care; taking care of, or assuming responsibility for care; care-giving; and finally, care receiving. Situated within those habits of care, attentiveness is understood as recognition, responsibility as a political ethic, competence as credibility, and responsiveness as deliberation (Tronto, 2013). Tronto's elements "inform us as citizens, and direct us to a politics in which there is, at the center, a public discussion of needs, and hones appraisal of the intersection of needs and interest" (2013, p. 168). For Tronto, there is no political theory, explicitly or implicitly, that does not contain an account of care (2013, p. 25). Although a useful working method, the original four habits and elements are reduced to traditional tropes of limited democracy, rather liberalism, which is also inherently exclusive of marginalized voices. However, Tronto's resilience at the intersection of private needs and public interest, we find a useful lens for thinking through private expressions of pain and the audience perception of that pain.

Where Gilligan is limited in relegating care to the private sphere—pain expression—and Tronto is limited by the four elements only associated with the public—perceived pain—we offer rhetorical care as an ideological endeavor, with a primary assumption that the personal is political; therefore we need additional elements to bridge the gaps between expressibility and perception. To that end, we introduce rhetorical care, as an organic critical cultural speculative lens, and defined as having two criterion: First, rhetorical care is intersectional, meaning an awareness of how and why overlapping identities challenge dominant oppressive ideologies; and second, a necessary fluidity for how healthcare epistemology is shaped by hegemonic status quo narratives that inherently exclude and marginalize certain voices.

A CASE FOR RHETORICAL CARE

Rhetorical care, for our purposes in this manuscript, builds on Gilligan's notion of care through essentialized identity work and Tronto's political theory work to make a case for a shift in the way scholars, and health professionals engage with women's pain. The theoretical and practical understanding of care is relational. Gilligan saw this relational tendency through attachment to one's gender identity, and Tronto sees relational capacity through democracy and its limitations. We see rhetorical care as both: essentially gendered, and ultimately motivated by challenging hegemonic oppressions. Within that framework, then, rhetorical care argues that agents of power must consider the ideological context for excluded and marginalized voices, specifically the relational and historical context of women's lived experience. Finally, rhetorical care is a vehicle which does not argue for intervention through sameness, but difference, where cultural competencies and counter-ideologies must be considered in contemporary health narratives. This is to say, if race and gender are not considered as functions in pain literacy; there is no chance for meeting Scarry's call for closing gaps in pain expressibility.

In this section of the manuscript, we will look to witness testimony as a descriptive and rhetorical lens for offering a larger discussion about ideological gaps in Black women's experienced pain, and their perceived pain, largely from white perspectives of healthcare. On September 27, 2018, the Subcommittee on Health for the United States House of Representatives met on the House Resolution (HR) 1318: Preventing Maternal Mortality. The theme of the hearing became clear; although every population in the United States was affected by mother and infant mortality—in startling rates for a developed country—the more palpable and urgent testimony and congressional questioning was about Black moms, and the gaps in care for that specific community.

The subcommittee on health is made up of 32 members of Congress. The demographics of the committee are largely reflective of Congress as a whole—mostly male, and mostly white. The task of the House Resolution, if implemented, was better data and outcomes in reducing maternal mortality in the United States (US). There are three startling facts of maternal mortality: first, the United States has the highest mortality rate among all developed nations; two, while mortality is decreasing in comparative nations, it is increasing in the US; and three, and most importantly for this analysis, there are considerable racial and ethnic disparities in the US (Centers for Disease Control Prevention, 2019b). According to the CDC's Pregnancy Mortality Surveillance System, between 2011 and 2015, pregnancy related mortality ratios indicated that there were approximately 43 deaths per 100,000 live births for Black women, to 13 deaths per 100,000 live births for white women. At the beginning of the hearing, Congresswoman Jaime Herrera Beutler opened with a statement as a co-sponsor of HR 1318, testimony then began with Charles Johnson IV, founder of 4Kira4Moms, Stacey Steward, President of the March of Dimes; Dr. Lynne Coslett-Charlton from the American College of Obstetricians and Gynecologists, and Dr. Joia Crear-Perry, President of the National Birth Equity Collaborative.

Mr. Johnson began his testimony expressing to the committee the happiness he and Kira Johnson shared when the couple first learned she was pregnant for a second time. That expression was soon followed by his devastation—in his words—Kira was now a "mortality statistic" along with the 50 K women who had died of complications in childbirth since 2015. Noting that statistic, women of color (Centers for Disease Control Prevention, 2019b), regardless of income and education, like Kira, were three-four times more likely to die. According to the CDC and Harvard's Chan School of Public Health, holistic medical reasons for increased pregnancy related mortality, specifically the racial and ethnic disparities, remains unclear. We contend, like others (Black Women's Health Study, 2019) that the gap in care is beyond medical positioning, but perhaps also related to the epistemological and ideological gaps between a Black woman's expressed pain, and the perceived reality of that pain, particularly among white providers.

Kira Johnson was a marathoner, and as Charles describes her, mobile, active, and full of life. Kira did not suffer from any of the leading medical conditions associated with maternal mortality rates, including, hypertension, heart disease, diabetes, or blood conditions. On the day of her labor, there were no medical complications in anesthesia, or infection. For all intents and purposes, Kira Johnson was the picture of health. Below, are segments from Charles Johnson's testimony about Kira's experience (United States House of Representatives: Subcommittee on Health, 2018):

We went in for what was supposed to be a routine scheduled Csection on what was supposed to be the happiest day of our lives and we walked right into what was our worst nightmare. After delivering another perfect baby, I was sitting next to Kira by her bedside in the recovery room. That is when I first noticed blood in her catheter. I notified staff immediately. A series of test were ordered. Along with a CT scan to be performed "STAT." I understood "STAT" to mean the CT scan would be performed immediately.

> Hours passed and Kira's symptoms escalated throughout the rest of the afternoon and into the evening. We were told by the medical staff at Cedars Sinai Kira was not a priority and we waited for her CT scan to be done… we waited for the hospital to act so she could begin her recovery. Kira kept telling me, "Charles, I'm so cold; Charles, I don't feel right." She repeated these same words to me for several hours.
>
> After more than 10 h of waiting. After 10 h of watching my wife's condition deteriorate. After 10 h of watching Kira suffer in excruciating pain needlessly. After 10 h of begging and pleading them to help her. The medical staff at Cedars Sinai finally took action. As they prepared Kira for surgery, I was holding her hand as we walked down the hall to the operating room. Kira looked at me and said, "Baby, I'm scared." I told her, without doubt, everything was going to be fine.
>
> The doctor told me I would see her in 15 min. Kira was wheeled into surgery and it was discovered that she had massive internal bleeding caused by horrible medical negligence that occurred during her routine C-section. She had approximately 3 liters of blood in her abdomen. Kira died at 2:22 a.m. April 17, 2016. Langston was 11 h old.

In unpacking the testimony of Johnson, there is one clear takeaway—pain was expressed over, and over, and over—and ultimately was not perceived with any serious medical attention or even curiosity. A marathoner and the picture of health, explaining her discomfort, that "she was so cold," and with blood visually in her catheter, told over and over that she was not a medical priority. Given what we know about maternal mortality, particularly among Black women, what would it have taken for her to be a medical priority? As Mr. Johnson emotionally told this congressional committee that she was begging for her life, it seems apt to speculate, that although Kira Johnson explained that she knew her body, and that something wasn't right, those exclamations and expressions of pain were not perceived with urgency or immediacy.

A key take-away in this case of Kira and Charles Johnson, and one all too familiar as pointed out by Amnesty International's report 2010, mortality rates are much more than health conditions, or quality access to maternal health care, but also social barriers like racial discrimination. Like Johnson, Alia McCants of Harlem, who at New York's Mount Sinai Hospital, almost died post labor from hemorrhaging, also believes that race was a factor in her care (Chuck, 2018). McCants' states "from the social worker who was visibly surprised by my husband and me as black professionals having twins, from the lack of empathy to her pain, and rushing her out of the hospital" … how much was the lack of care due to "because I was black." Another example, Jaymie Rivera-Clemente of Texas, who identifies as Black and Latina, describes lack of care ranging from outright dismissal, to the more subtle micro-aggressions of physician's offices; questions to Rivera-Clemente like "do all of your kids have the same father" (Chuck, 2018). Johnson, McCants, and Rivera-Clemente are not alone. According to a survey done in partnership with NPR, the Robert Wood Johnson Foundation, and the Harvard T.H. Chan School of Public Health, 32 percent of Black women surveyed reported that they have been discriminated against in physician's offices (Discrimination in America, 2017). Quoting a talk given by Ana Langar, the coordinator of Harvard's Women's Health Initiative at the Harvard Chan School of Public Health, Roeder (2019) cites, "Women—particularly those who are most vulnerable due to their race, age, or socioeconomic status—receive less attention overall for their health issues, compared to men." More specifically, Elizabeth Dawes Gay, of BlackMamasMatter.org, argues:

> Those of us who want to stop black mamas from dying unnecessarily have to name racism as an important factor in black maternal health outcomes and address it through strategic policy change and culture shifts. This requires us to step outside of a framework that only looks at health care and consider the full scope of factors and policies that influence the black American experience. It requires us to examine and dismantle oppressive and discriminatory policies. And it requires us to acknowledge

> black people as fully human and deserving of fair and equal treatment and act on that belief (Roeder, 2019).

Following Johnson's testimony, Stewart of the March of Dimes followed with statistics and how a bill like this would close gaps. She also pointed out that this was a holistic issue where there is not a single answer for a single problem, building on Johnson's testimony stating:

> The causes of maternal mortality and severe maternal morbidity are diverse. They include physical health, mental health, social determinants, and much more. They can be traced back to the issues in our healthcare system including the quality of care as we just heard so passionately from Charles, systems problems, and of course the issue of implicit bias that exist in our healthcare system. They stem from factors in our homes, our workplaces, and our communities.

Dr. Raymond Cox, a former OB-GYN and now with "Volunteers in Medicine," is working to alleviate implicit bias in trainings, and in the language of care between doctors and patients. Dr. Cox states that he has seen implicit bias on every level of medical treatment and has witnessed patients treated differently because of race, offering "Doctors tend to spend less time and tend to assume that the Black or Latino patient isn't going to understand what we're talking about, and as a consequence, have a tendency to make decisions for that patient" (Chuck, 2018). Again, we have this explanation point on the fact that there are other factors at play beyond medicine.

The final testimony of the hearing was from Dr. Crear Perry, an obstetrician, and also a member of the American College of Obstetricians and Gynecologists. Her testimony was a follow up to her colleague's Dr. Charlton, who spoke of unique gains in unique state situations, like California that had a decreasing maternal mortality rate. Dr. Perry however added that although California is seeing fewer deaths among new mothers in the state, the deaths among Black women has increased. Dr. Perry's testimony takes dead aim at the ideological limitations of maternal health. She argues, "the legacy of a hierarchy of human value based on the color of our skin continues to cause differences in health outcomes, including maternal mortality. Racism is the risk factor—not Black skin. There is no "Black" "gene" (HR 1318 testimony). She then followed with her own narrative, where her now 22 years old son was born premature in a hospital named Confederate Memorial, and talked to the committee members about what was considered "normative" prejudicial behavior with her as the patient, and a medical resident at the time. In closing, Dr. Perry states—in tone—demands,

Ultimately, what Black women in the U.S. need is accountability. We need to know that our lives are valued. This accountability may be complicated, but government still has an obligation to act. Racism, classism and gender oppression are killing all of us, from rural to urban America.

This is not about intentions. Lack of action is "unintentionally" killing us. It is a human rights imperative. Throughout the bill, there is no mention of race, racism, or racial disparities. The inability to name this as a key focus to reduce RACIAL disparities in maternal mortality and morbidity will continue to exacerbate the problem. We must ensure that prevention efforts and resources are being directed toward the areas of greatest need and be willing to name the problem directly.

> Much can be accomplished through improved monitoring and data collection. H.R.1318 is a tremendous step forward in showing that we do recognize… Yes, Black Mamas Matter.

Dr. Perry does not leave much to the imagination, and serves here to illustrate the gap that this manuscript has been negotiating; Dr. Perry points directly toward racism as a medical factor in addressing the gap in care between Black mothers and their health care providers.

DISCUSSION

We contend that voicing pain, rather, pain expressibility is more than an epistemological endeavor. Certainly, linguistic functionality is part of pain expression. As Scarry (1985) and Bustan (2016) would illustrate, certain "common practices" of language allow for and demand articulation between pain expression and perception. For example, if I say "my head hurts" there is a common practice on the continuum of expression-perception-treatment. The common perception would most likely result in "take a pill, it will pass." The idea of "common practice" is a normative communicative function in health communication, with normative conditions and expectations. But as we have shown throughout this essay, race—and othering because of race—challenges the normative, in that "common practice" is more challenging for underrepresented, often marginalized, and stigmatized populations. There is a gap in articulation—epistemological, and as we have argued, ideological.

To understand a holistic view of pain literacy, we have argued that there are ideological currents to explain gaps in pain care. Scarry gives us a launching point as she focused on the agency of pain, rather than physical pain, which was tautological, had agency; the person expressing pain, had agency. We too, are concerned with agency, but its limitations, which is to say, we have illustrated in these case examples, that there are also gaps in who has agency. As a result, it seems that we do not pay enough attention to the agency of perceived pain, rather, how cultural and racial competencies play a role in de-limiting agency for those who fall outside of normative conditions of pain articulation.

To that end, we introduced rhetorical care, as an intervention into the pain literacy literature housed in health communication, where the care lens strives to be intersectional, calling for a cultural awareness and competence that is epistemologically nuanced. We certainly acknowledge that there are many medical factors and variables in the cases of Kira Johnson, Alia McCants, Jaymie Rivera-Clemente, and even Serena Williams. What we hoped to introduce by expanding on these examples were gaps in language perceptions where race was a material and symbolic factor in each case. We are not medical professionals, and we can never know for sure what led to the all too common realities of each example introduced, but we argue as rhetorical and health communication scholars that race and gender must be considered as primary factors in negotiating the journey from pain expression to pain perception and ultimately, pain treatment. As mentioned above, diagnostic delays happen at a greater rate for women than men when women express pain (Selvam Paramasivam et al., 2017). Additionally, Hoffmann and Tarzian (2001) suggest that expressions of pain from women may not be taken as seriously when describing or seeking help for their pain. Finally, we would argue that from the lenses of Washington (2006), Barr (2010), and Arrington (2015), race is a factor when considering epistemological and ideological gaps in healthcare.

Specifically, to address bridging ideological gaps in pain literacy, which we see as the rhetorical life of pain expression to pain perception, we argued for a heuristic shift, defined as rhetorical care. Rhetorical care as it builds on Gilligan's (1982) notion of care through attachment identity work and Tronto's (2013) political theory work, we make the case for a shift in the heuristic of pain literacy. From a theoretical perspective, we build from and add to the four original elements of care by asserting that rhetorical care is intersectional, epistemologically nuanced as language relates to race and cultural competencies, and argues that agents of power must consider the ideological context for marginalized communities, specifically in gendered and racial pain literacy gaps. From a material and applied perspective, we assert that pain literacy from a perspective of rhetorical care could expand on health professional trainings, such as implicit bias trainings, or provide a launching point for further data collection and testing for monitoring ideological gaps in care for marginalized communities, and ultimately serves to intervene and bridge those divides.

DATA AVAILABILITY STATEMENT

All datasets analyzed for this study are cited in the article/supplementary material.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct and intellectual contribution to the work, and approved it for publication.

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Fundamentals of Social Identity and Social Justice: Considering Social Identity Within CBPR With Marginalized Populations

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Community-based participatory research (CBPR) is a research paradigm that works with marginalized populations within health contexts. The partnership between scholars and marginalized populations empowers participants through the pursuit of social justice. However, there has been a cry for standardizing the CBPR approach particularly when working with marginalized populations. Identity is a critical construct to understand within the communities in order to collectively strive toward social justice. This paper examines how social identity theory can aid community-based participatory research teams by (a) illustrating how social identity analysis can facilitate the researcher-community partnership, (b) applying SIT to better understand community behaviors and norms, and (c) using SIT to avoid unintended consequences within CBPR intervention designs. Through understanding identity, relational empowerment can be positively redistributed back to community members. This paper will thus serve as a first step in justifying why more research is needed in incorporating social identity to CBPR intervention designs.

Keywords: social identity, community-based participatory research, community engaged research, social justice, intergroup communication

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INTRODUCTION

Over the past few years the popularity of community-based participatory research (CBPR) has drastically increased (Simonds et al., 2013; Brown and Stalker, 2018), and scholars seem captivated by the applied aspects of the approach. CBPR is a research paradigm (Minkler and Wallerstein, 2003) that has researchers working in equal partnership with marginalized community members to work on health issues that directly affect the community (McAllister et al., 2003; Abma et al., 2017; Brown and Stalker, 2018). CBPR works on social justice issues and policy change based on historical inequality in marginalized communities (Devia et al., 2017). Starting in the public health discipline (Israel et al., 1998), CBPR has influenced the disciplines of nursing, clinical care, social work, community psychology, and communication (Minkler and Wallerstein, 2011). According to McAllister et al. (2003), there are five tenets to CBPR: (1) the formation of the researcher-community partnership prior to the research, (2) sufficient support for the community partners, (3) a commitment to research that is applied within communities, (4) developing empirical research designs, and (5) shared ownership of the project data between the researchers and the community members. Critical to the ideology of CBPR, the marginalized communities are not the only ones learning from the process, rather scholars and communities learn together from the process through dialogue (Israel et al., 1998; Minkler and Wallerstein, 2011). Freire (1970) posited that dialogue is the process of understanding, interpreting, and transforming their reality (For further reading on co-learning and dialogue, see Freire, 1970).

One of the most frequent justifications for the use of CBPR is when a community is engaged within the project, empowerment and community buy-in increases, which helps to ensure the long-term success of health interventions (McAllister et al., 2003; Castro et al., 2004). Empowerment is not merely participation, but the process by which communities regain control over factors that influence their lives (Baum, 2008). The most common types of empowerment are relational power and power in capacity (Chaskin, 2001; Boyle and Silver, 2005). Capacity building power encompasses skills development (Chaskin, 2001), while relational power focuses on the power of a group in relation to others (Boyle and Silver, 2005). Much research has been done on building capacity power, but equally important is analyzing the power relationship between researcher and community (Boyle and Silver, 2005). CBPR is a method that can positively aid social justice action in health (Israel et al., 1998; Minkler and Wallerstein, 2011; Simonds et al., 2013). Islam et al. (1991) explained that social justice issues are dynamic and multi-dimensional problems that are not always easy to solve or document. Because CBPR works with communities, the paradigm helps create innovative interventions that better account for community needs and creates unique evaluation tools to fit the intervention goals and objectives (Islam et al., 1991).

CBPR has been applied as a spectrum encompassing varying levels of community research participation (Butterfoss, 2006; Peterson and Gubrium, 2011; Jordan, 2016). However, this means there is not a standard method of implementation (Butterfoss, 2006; Wallerstein, 2006; Peterson and Gubrium, 2011; Brown and Stalker, 2018). Specifically, when working with marginalized populations on health interventions, scholars have indicated a need for more analysis into (a) how community members co-create the intervention (Snyder, 2007; Rimal and Lapinski, 2009) and (b) how the researcher and community team members communicate throughout the intervention (Butterfoss, 2006; Brown and Stalker, 2018; Chak, 2018). Some literature has examined the group communication within intervention teams composed of researchers and community members (Lantz et al., 2001; Christopher et al., 2008; Israel et al., 2010). However, very little research uses theory to guide the intervention communication plan between researchers and communities within CBPR. Given that CBPR teams include multiple groups of people, intergroup theories can help CBPR scholars better understand and explain intergroup behaviors and motivations.

One such theory is social identification theory (SIT), which assumes that individual identity is shaped by perceived membership into groups (Tajfel and Turner, 1979). Social identity is critical to understanding power and social justice (Jetten et al., 2012). According to Artz and Murphy (2000), social justice for marginalized populations requires the marginalized groups to construct meaning for themselves (Papa et al., 2006). (Papa et al., 2006) argued that for marginalized groups to become empowered, they must fully understand their identity and world perception. In addition, Jetten et al. (2012) argued that understanding identity has the potential to "contribute to a "social cure" that is capable of promoting adjustment, coping, and well-being among individuals who are dealing with a range of illnesses, injuries, traumas, and stressors" (p. 5). Social identity theory has been used to explain and predict group behaviors and norms (Hogg and Turner, 1987a; Jetten et al., 2012), making the theory fundamental to many health intervention designs (Jetten et al., 2012). However, scant research has explored the impact of social identity specifically within CBPR.

Many scholars argue that CBPR interventions would benefit from rigorous approaches to CBPR (Peterson, 2010; Peterson and Gubrium, 2011; Wilson et al., 2018). Scholars also question the accuracy of CBPR applications throughout the research process (Butterfoss, 2006; Chak, 2018). As Lewin (1951), one of the founders of Action Research, stated, "there is nothing so practical as a good theory that affects practice" (p. 169). In an effort to meet the growing need for standardization and rigorous applications of CBPR, this paper examines how SIT can aid CBPR scholars and teams by (a) illustrating how social identity analysis can facilitate the researcher-community partnership, (b) applying SIT to better understand community behaviors and norms, and (c) using SIT to avoid unintended consequences within CBPR intervention designs. Health intervention designs need to be cognizant of the dynamic process of identity specifically when targeting marginalized populations in order to avoid unintended consequences, build stronger partnerships, and to uphold social justice. This paper will serve as a first step in justifying why more research is needed in incorporating social identity to CBPR intervention designs.

SOCIAL IDENTITY THEORY (SIT)

Identity is a dynamic process that involves evaluation in which the individual continually self-categorizes their in-group membership (Tajfel and Turner, 1979; Turner, 1999). SIT posits that individual identity is layered with memberships within multiple social groups (Tajfel and Turner, 1979). SIT does not predict individual-level beliefs or attitudes toward the social group, but rather takes a holistic look at the group and the structures in place that impact both the behaviors and the identification of groups, which ultimately impact individuals (Turner, 1999). Through observing group dynamics and behaviors, and communicating with group members (Odenweller and Harris, 2018), individuals understand the standard set of practices and beliefs of the group (Hogg and Terry, 2002).

Individuals within groups commonly compare their group to other groups in order to gauge positive distinctiveness (Tajfel and Turner, 1979). Positive distinctiveness is the belief that a group is superior to others, which is critical to maintaining group members and group identification because individuals must believe that their self-image is being positively influenced by membership in a specific group (Tajfel and Turner, 1979; Hogg and Turner, 1987b). SIT proposes a spectrum called the interpersonal continuum to understand how individuals perceive their group by comparing it to other groups, also referred to as out-groups (Tajfel and Turner, 1979). If the in-group is seen as less favorable as compared to an out-group, there are three strategies individuals can take to maintain positive distinctiveness: (1) individual mobility, (2) social creativity, and (3) social competition (Tajfel and Turner, 1979; Turner, 1999). If the positive distinctiveness of the group is threatened by negative associations, individuals may choose to distance themselves from the group or leave the group, which is called individual mobility (Tajfel and Turner, 1979). Individual mobility assumes that the boundaries of the group are adjustable or permeable (Ellemers et al., 1990). Social creativity occurs when individuals are motivated to protect the group, so they adapt or change the group's attributes or behaviors to appear more favorable (Tajfel and Turner, 1979; Haslam et al., 2001). Social creativity can involve adding new attributes to the in-group in order to balance out the threats to positive distinctiveness, or bolstering the already existing positive attributes of the group (Haslam et al., 2001). Finally, social competition, confronts out-group members directly about the negative stereotypes to their in-group membership (Haslam et al., 2001). The moderators to the choice of strategy include group characteristics like hierarchy, the level of commitment the individual has to the group, and the group stability (Tajfel and Turner, 1979). SIT allows scholars to see identity not as a category, but rather a dynamic process (Usborne and Taylor, 2010).

SIT AND CBPR PARTNERSHIPS

Critical to CBPR is the idea that there are equal partnerships between the researcher and community partners (Israel et al., 1998). As previously discussed, relational empowerment refers to the power renegotiation between the researcher and the community (Boyle and Silver, 2005). However, by having the researcher define the unit of shared identity within a community, the relational power dynamics are already skewed to give more power to the researcher. Understanding the identification process of a marginalized community is an imperative component of the first tenet of CBPR, which is the formation of the researcher-community partnership (McAllister et al., 2003). SIT analysis requires communities to define their own identity, thus relational power is positively redistributed back to the community by fully understanding their own identification process. Identity deconstruction is critical to empowerment (Papa et al., 2006), so CBPR efforts to increase empowerment within marginalized communities can be facilitated through understanding identity. Standard CBPR practices pre-define the community identification, which limits the communities' conversations that fall outside of those parameters leading to group othering (Papa et al., 2006; Brown and Pehrson, 2019).

SIT AND UNDERSTANDING COMMUNITY BEHAVIORS AND NORMS

The community within CBPR projects is defined as any form of mutual identification or social ties (Israel et al., 1998). In practice, the researchers often assign the parameters of identification to a community by a health issue, race, geographic area, or age demographic. While these categories allow for clear community definitions, they don't allow communities to define their own identification, which is counter to the philosophy of CBPR (Israel et al., 1998; Minkler and Wallerstein, 2011) and is not in spirit with the social justice requirement of allowing communities to construct meaning for themselves (Papa et al., 2006). Unique to participatory research paradigms is the self-assignment of community members (Israel et al., 1998). This is important because understanding what mutual ties communities see for themselves would allow scholars to have a rich understanding of community beliefs, behaviors, and norms, which is imperative to creating efficacious CBPR interventions (Israel et al., 1998). SIT analysis would also allow scholars to see the strengths of social identity within communities (Usborne and Taylor, 2010).

Finally, SIT can help CBPR teams develop interventions that are more culturally competent. SIT posits that individuals want to maintain a positive self-concept (Tajfel and Turner, 1979; Turner, 1999). An in-depth analysis of the identity of community members would provide key analysis into the culture and cultural practices of a community (Devia et al., 2017; Wallerstein et al., 2017). For example, Devia et al. (2017) argued that understanding the culture of communities facilitates positive group dynamics as well as facilitating long-term success of the intervention. Understanding the identification of a community is critical to understanding the community itself. If CBPR scholars take the time to understand how communities achieve positive distinctiveness, SIT can help scholars combat the deficit model and understand the strengths of the community better. The communities' processes of achieving positive distinctiveness can then be included within intervention designs (Jetten et al., 2012). Including the identification process within the intervention design supports Israel et al. (1998) argument that CBPR needs to have a holistic perspective of the communities' social structures, which in turn influences the capacity building outcome of the CBPR intervention. Thus, SIT considerations in CBPR designs can establish the framing of the message in a way that is conducive to the community identity (Chaskin, 2001; Wallerstein et al., 2008; Minkler and Wallerstein, 2011).

SIT AND MANAGING UNINTENDED CONSEQUENCES IN CBPR

SIT can also help CBPR scholars navigate the unintended consequences of homogenizing community members. As Cho and Salmon (2006) argued, there will always be unintended consequences to any intervention. However, researchers should attempt to predict potential unintended consequences through multi-level analysis (Cho and Salmon, 2006). Communities within CBPR projects are marginalized (Israel et al., 1998; Wallerstein, 2006; Minkler and Wallerstein, 2011). On a macro-scale, the community could also have lower status and power within society. As SIT proposes, groups encountering threats to positive distinctiveness can address conflict through social creativity, social competition, or individual mobility (Tajfel and Turner, 1979). While members of a community might share traits or characteristics that lend themselves to being defined as singular units of identity, marginalized community members may deal with in-group conflict differently (Tajfel and Turner, 1979; Haslam et al., 2001; Usborne and Taylor, 2010). For example, Huse and Wendorf Muhamad (2018) examined the social identification of Appalachians, a cultural group within the United States who have been marginalized and stereotyped as unintelligent hillbillies (Billings et al., 1999; Algeo, 2003; Tighe, 2007; Cooke-Jackson and Hansen, 2008; Wood and Hendricks, 2009). In order to address these stereotypes associated with Appalachia, Appalachians strived toward positive distinctiveness by either promoting the positive attributes of the community or by disassociating from the group entirely (Huse and Wendorf Muhamad, 2018). When analyzing social identities that aren't permeable (e.g., race, sex, sexual orientation), members of a marginalized community may choose to disassociate from the group in order to maintain a positive self-concept (Huse and Wendorf Muhamad, 2018). By seeing community identity as a dynamic multidimensional process, CBPR scholars could be less likely to homogenize communities to singular traits of identification (Morley and Robins, 2002) such as geography, religion, or cultural association.

Homogenizing a community to singular units of identity could lead to unintended consequences on mico-, meso-, and macro-scales. First, because individuals may use different strategies to achieve positive distinctiveness, CBPR interventions that homogenize communities may have different reactions from different people, and could have unintended consequences. Interventions could unintentionally divide people who use different strategies to achieve positive distinctiveness, and make some feel isolated or blamed for the intervention health issue. In addition, if the intervention message doesn't consider individuals who use individual mobility, a boomerang effect could ensue (Cho and Salmon, 2006). Although CBPR tries to shed light on unintended consequences, where there is action there will be unintended effects (Cho and Salmon, 2006).

The latent effects of not considering social identity within interventions could permeate to multiple fields of influence. Cho and Salmon (2006) argued that an unintended consequence of viewing a community from a systems level approach (like SIT) could lead to multilevel influence of unintended consequences by stating:

> "Individuals may carry the intended meanings to unintended levels and contexts through subsequent communicative actions, and the social environments surrounding them may direct the process and outcomes of a campaign to unintended contexts and levels." (p. 296)

The consequences of intervention may affect an individual, but may also affect the larger communities' levels of identification (Cho and Salmon, 2006). In order to understand the ripple effect action may have, a system-level analysis on the identification process of the community could mitigate the unintended consequences within CBPR designs (Cho and Salmon, 2006).

LIMITATIONS TO APPLYING SIT TO CBPR

The most significant barrier in applying SIT to CBPR requires analysis into the method of identity deconstruction and testing. Without knowing who the community is, finding a pairing between scholars and communities based on common interests would be difficult. The methodology for determining social identification within a community would also be difficult. While traditional methods of social identity are surveys, many marginalized communities may feel alienated from the process of distributing a survey (Minkler and Wallerstein, 2011). Non-traditional approaches such as participatory ethnographic methods (e.g., photovoice, see Wang and Burris, 1997; or narrative journaling see Hubbert et al., 1999), or narrative interviews or dialogue circles (Barz and Cohen, 2011), should be explored as potential data collection methods for examining SIT.

Because SIT is a specific theory with potential problems in application, researchers need to test SIT within the field of CBPR. If SIT is insufficient in examining the context of CBPR, the broader identification approach, which includes self-categorization theory and principles of SIT, could then be tested for its applicability to CBPR (Turner, 1999). Utilizing the CBPR practice of dialogue, scholars can attempt to co-learn the communities' identification with them.

DISCUSSION

Taking the time to understand community identity is critical when considering the social justice elements of CBPR. The paradigm of CBPR strives to combat social justice inequalities, but the process of achieving change is critical in pursuing social justice (Israel et al., 1998; Minkler and Wallerstein, 2011). Social identity is critical to social justice (Papa et al., 2006). According to Artz and Murphy (2000), as previously argued, by Artz and Murphy (2000) identity as defined and understood by the community should be a critical step of pursuing social justice within CBPR intervention designs (Papa et al., 2006).

This paper examined how SIT can aid the mission of CBPR, which is to empower marginalized populations through participation in the research process (Israel et al., 1998). Social identity can help scholars by (a) illustrating how social identity analysis can facilitate the researcher-community partnership, (b) applying SIT to better understand community behaviors and norms, and (c) using SIT to avoid unintended consequences within CBPR intervention designs. As the cry for standardized approaches to communication with marginalized populations continues, intergroup communication theory can be the key to helping to navigate, understand, and explain identity of marginalized communities. SIT analysis could be the best way to protect the social justice for marginalized populations in which CBPR teams serve.

AUTHOR CONTRIBUTIONS

L-KH conceived the idea of the study, reviewed the literature, and wrote the final manuscript.

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REVIEW
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Effectively Communicating About HIV and Other Health Disparities: Findings From a Literature Review and Future Directions

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Despite significant progress in the prevention and treatment of HIV, disparities in rates of infection remain among key groups in the United States, including blacks and African Americans; Hispanics/Latinos; and men who have sex with men (MSM). The U.S. Department of Health and Human Services' initiative, *Ending the HIV Epidemic: A Plan for America*, calls for addressing HIV-related disparities and reducing stigma and discrimination associated with HIV. The goal of this literature review was to identify approaches for effectively communicating about health disparities across the HIV care continuum. We reviewed the literature to investigate strategies used to communicate health disparities and to identify potential unintended adverse effects resulting from this messaging. Messages about health disparities often target subgroups at higher risk and can be framed in a variety of ways (e.g., social comparison, progress, impact, etiological). Studies have examined the effects of message framing on the risk perceptions, emotional reactions, and behaviors of individuals exposed to the messaging. The evidence points to several potential unintended adverse effects of using social comparison framing and individual responsibility framing to communicate about health disparities, and visual images and exemplars to target messages to higher-risk subgroups. There is not yet a clear evidence-based approach for communicating about health disparities and avoiding potential unintended effects. However, we offer recommendations for communicating about HIV-related disparities based on our findings. Because we found limited literature that addressed our research questions in the context of HIV, we propose a research agenda to build an evidence base for developing effective messages about HIV-related disparities.

Keywords: HIV, disparities (health racial), health communication, message framing, stigma, stereotype, targeting, unintended adverse effects

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INTRODUCTION

Healthy People 2020 defines a health disparity as "a particular type of health difference between individuals or groups that is unfair because it is caused by social or economic disadvantage" (U.S. Department of Health and Human Services, 2008). Despite significant progress in the prevention and treatment of HIV in the United States, disparities remain in rates of infection among racial/ethnic minority groups, with black and African American (hereafter referred to as black) and Hispanic/Latino populations being the most affected subgroups (McCree et al., 2017; U.S. Department of Health and Human Services, 2020). Gay, bisexual, and other men who have sex with men (MSM) are also disproportionately affected by HIV, and most MSM diagnosed with HIV are MSM of color. The causes of these disparities are complex and interrelated and can be attributed to multiple individual, social, contextual, and environmental factors (McCree et al., 2016).

Ending the HIV Epidemic: A Plan for America is the U.S. Department of Health and Human Services' cross-agency initiative that aims to reduce new HIV infections in the U.S. by 90% in 10 years by focusing on communities most impacted by HIV (U.S. Department of Health and Human Services, 2020). This initiative highlights the persistence of HIV disparities among racial and ethnic minority groups as well as MSM and the role of stigma in preventing those at risk for HIV or living with HIV from receiving needed health care and services. HIV stigma may be exacerbated in marginalized groups who experience multiple and converging forms of stigma—referred to as intersectional stigma—including stigma related to race, ethnicity, sexual identity, gender identity or expression, illicit drug use, sex work, and incarceration (Earnshaw et al., 2013; Rice et al., 2018). Stigmatizing attitudes toward people with HIV or at risk for HIV may lead to delayed HIV testing (Golub and Gamarel, 2013), reduced adherence to antiretroviral therapy (Sweeney and Vanable, 2016), and poorer retention in care (Yehia et al., 2015). Social stigma can also have serious negative consequences for both psychological and physical well-being by decreasing self-esteem and increasing stress responses in stigmatized groups (Major and O'Brien, 2005).

Health communication can play a key role in raising awareness among priority audiences about their risk for getting or transmitting HIV and influencing attitudes, beliefs, and behaviors. However, communicating about health disparities can also result in unintended, adverse consequences. For example, dissemination of information comparing HIV diagnoses by subgroup may result in "blame and shame" and foster helplessness, distress, anger, and mistrust among affected communities (Friedman et al.'s, 2014; Lee et al., 2017; Drumhiller et al., 2018).

Smith (2007) developed a model of the social and psychological effects of messages that communicate stigma. According to Smith, stigma messages have four characteristics: (1) they distinguish or categorize a group of people, (2) they establish this group of people as a separate social entity, (3) they link the group to a physical or social threat, and (4) they imply that group members are responsible for the threat. Thus, stigma messages encourage stereotyping and the perception of the group as a coherent entity and make social identity salient (Major and O'Brien, 2005; Smith, 2007). These messages contribute to the perception of stigmatized individuals as a social threat and as responsible for their condition (Smith et al., 2019). Negative behavioral outcomes of exposure to stigma messages include increased support for interventions that isolate and regulate stigmatized groups, interpersonal disassociation from stigmatized individuals, and the social transmission of stigma messages (Smith et al., 2019). Because HIV and groups at greater risk for HIV are often associated with multiple social stigmas, communication about HIV and disparities in HIV are particularly susceptible to containing characteristics of stigma messages. Consequently, a better understanding of message strategies and features that raise awareness and motivate behavior change while avoiding potential adverse effects is needed.

We designed this literature review to be exploratory in nature. The overarching goal of the review was to identify promising approaches for effectively communicating about disparities across the HIV care continuum. As such, we reviewed the literature to address the following research questions (RQs):

1. What strategies are used to communicate health disparities information?
2. What are the potential unintended adverse effects of messages communicating health disparities, and how do specific message strategies contribute to these effects?

METHODS

We searched four databases—PubMed, Web of Science, PsycINFO, and Communication Source—using the search terms shown in **Table 1** for peer-reviewed literature published between 2011 and 2018. This time frame was selected to focus the review on the most recent literature that addressed our RQs. We also obtained additional articles *via* the snowball method, which involved reviewing the reference lists of particularly relevant articles and acquiring articles recommended by colleagues with subject matter expertise. Because the number of relevant articles identified by the database search was relatively small, we did not place any limitations on the time frame for articles obtained with the snowball approach.

We focused the search on studies conducted in the United States; however, we also included two articles from other countries because they examined RQs closely aligned with those of interest in this review. One study, identified by the snowball method, was conducted in South Korea (Lee and An, 2016) and described a randomized experiment testing the effects of messages about the controllability of a condition (i.e., individual responsibility for the onset of a condition) and group categorization on perceived stigma. The other study, conducted in the United Kingdom, reported results of interviews conducted to learn about the unintended consequences of an intervention targeting a high-risk group (Sorhaindo et al., 2016).

Although we prioritized literature focused on HIV, this body of literature was small. Consequently, we did not limit our search to HIV. We included relevant literature addressing our RQs across health topics, including sexually transmitted diseases (STDs), cancer, mental health, and obesity. Though some higher-risk populations may experience more layers of stigma than others, which could affect responses to messaging, we expected potential responses to messages about health disparities to be a communication phenomenon that would be similar across conditions, rather than entirely condition specific.

TABLE 1 | Literature search overview.

	Database search	Snowball method
Time period	2011–2018	1996–2018
Language	English only	English only
Location	U.S. focus	U.S. focus
Sources	• PubMed • Web of Science (includes Science Citation Index Expanded, Social Sciences Citation Index, and Conference Proceedings Citation Indexes for Science and Social Science & Humanities) • PsycINFO • Communication Source	• Reference lists of relevant published articles • Colleagues with subject matter expertise
Keywords (first level)	[“message framing” or “priming” or “targeting” or “health message” or “health communication” or “health information” or “public service announcement” or “campaign”] AND [“health disparities*” or “racial disparities*” or “health equity*” or “racial stigma*” or “stigma* or “stereotype” or “intergroup differences”] OR [“health risk estimates*” or “health risk*” or “risk*”] OR [“perceived susceptibility*” or “perceived risk*”]; **AND**	Not applicable
Keywords (second level)	[“Black” or “African American”] or [“Hispanic” or “Latino”] OR [“MSM” or “men who have sex with men”] OR [“homosexual” or “gay” or “bisexual”] OR [“transgender” or “transsexual”] OR [“minority”] or [sexual minority or gender minority]; **OR**	Not applicable
Keywords (third level)	[“unintended effects” or “unintended consequences” or “iatrogenic effects”] OR [“ethical considerations”]	Not applicable
Publications and other documents worthy of full-text review	39	50
Excluded because of a lack of relevant information	19	27
Total publications and other documents reviewed	20	23

Thus, we wanted to draw on the body of literature examining this phenomenon.

We were systematic in our approach to identifying relevant literature. However, the goal of this literature review was to be inclusive of relevant studies that addressed our RQs—including both quantitative and qualitative research—to gain an understanding the state of the science. Because the body of literature addressing our RQs was limited, we included a broader range of studies than would be included in a systematic review, which requires that studies meet certain specifications for design and quality. Broadening the body of literature we reviewed also allowed us to better synthesize literature at the intersection of our topics of interest and identify gaps in the existing literature.

We scanned titles and abstracts to identify potentially relevant articles and other documents, which resulted in 89 articles, book chapters, and reports for further review. On the basis of this review, we excluded sources that were not focused on our RQs, such as those that compared gain and loss frames rather than different strategies for framing disparities information. In total, we identified 43 articles and other documents from which we abstracted information that addressed the RQs.

RESULTS

We found limited literature specifically addressing the RQs in the context of communicating HIV-related disparities (11 articles focused specifically on HIV and 3 on other STDs). Research assessing strategies and approaches used to communicate about health disparities often focused on cancer (e.g., Nicholson et al., 2008; Landrine and Corral, 2015), whereas much of the research about stigmatization and stereotyping focused on mental health (e.g., Corrigan et al., 2012, 2015), and obesity (e.g., Skurka, 2019). Only a few studies provided insights into how disparities in STDs and HIV can be presented to promote behavior change and avoid unintended adverse effects (Friedman et al.'s, 2014; Uhrig et al., 2017; Drumhiller et al., 2018).

We begin by describing strategies used to communicate health disparities. We then discuss potential unintended adverse effects that can result from the use of these strategies.

Strategies for Communicating Health Disparities Information

Targeting and framing are communication strategies often used in messaging about HIV and other health disparities. In this section, we review literature that addresses our first RQ.

Targeting

Targeting, also referred to as audience segmentation, is a strategy used to increase the effectiveness of health messages and information (Slater, 1996). Targeting involves the decision to direct public health messages to a particular segment or segments of the population (i.e., priority audience), typically groups considered to be at “high risk” (Kreuter and Wray, 2003; Guttman and Salmon, 2004). The rationale for developing targeted messages is that they will better address the needs, concerns, beliefs, and values of a particular subgroup; increase the likelihood that the messages will be perceived as relevant; and promote positive behavior change (Slater, 1996; Institute of Medicine, 2002; Kreuter and Wray, 2003).

Message Framing

Message framing involves "select[ing] some aspects of a perceived reality and [making] them more salient in a communicating text" (Entman, 1993). Entman also describes frames as "defining problems," "diagnosing causes," "making moral judgments," and "suggesting remedies." The way information is framed is important because it has implications for how people view and understand the topic addressed in the communication (Entman, 1993). Frames can be used intentionally or unintentionally to communicate about health risks in public health messages and in the news media.

Framing is a strategy commonly used in messages about health disparities. We found that messages frame information about health disparities in a number of ways. *Social comparison framing* typically highlights disparities in disease incidence, risk, or outcomes between racial or other groups; for example, "Blacks are more than twice as likely as whites to be diagnosed with HIV" (Dunham et al., 2016). *Progress framing* highlights progress made in reducing health disparities, such as "Blacks Making Great Strides Against Colon Cancer" (Landrine and Corral, 2015). *Impact framing* presents the risks for one subgroup only (e.g., black only or white only). *Non-comparative framing* presents risks for the population overall (e.g., Americans; often used as a control in studies). *Etiological framing* or *causal framing* is when messages are framed to emphasize one or a combination of causal factors.

A small body of experimental studies examined the effects of message frames for communicating about health disparities on the risk perceptions, emotional reactions, behavioral intentions, and behaviors of priority audiences (i.e., those at higher risk) and those outside the priority audience. **Table 2** provides an overview of these studies ($n = 13$) that address our first RQ. We discuss these studies in more detail below.

Social comparison framing

Several studies have examined the effects of presenting risk information in messages using a social comparison frame vs. messages using a non-comparative frame on participants' risk perceptions, emotional reactions, and other outcomes (Uhrig et al., 2013; Bigman, 2014; Dunham et al., 2016; Jones et al., 2016; Skurka, 2019).

In a series of experiments, Bigman (2014) found that social comparison framing (comparing blacks and whites) of STD and cancer risk in mock news articles did not significantly raise risk perceptions among the group at higher risk (i.e., blacks in the case of STDs) relative to non-comparative and impact frames (Americans, blacks only, or whites only) containing equivalent information. However, the social comparison frame had an unintended effect of *lowering* the risk perception for the group at lower risk (i.e., whites in the case of STDs). Dunham et al. (2016) investigated whether messages about HIV and diabetes using a social comparison frame would increase risk perceptions among blacks (the group at higher risk) relative to non-comparative control messages that did not mention race. The messages using a social comparison frame did not significantly increase risk perceptions among blacks, compared with the non-comparative messages.

Other studies examined the effects of social comparison frames in the context of cardiovascular disease and obesity. Jones et al. (2016) found that public service announcements (PSAs) using a black-white social comparison frame for presenting cardiovascular disease risk negatively affected task persistence (i.e., completing a health assessment form), especially among blacks, relative to PSAs on neutral health topics (air pollution, forest fires, and wearing seatbelts). Skurka (2019) examined the response to obesity messages that used racial (blacks at higher risk than whites) and geographic (rural individuals at higher risk than urban individuals) social comparison frames. Participants exposed to the racial comparison frame were more likely to accept the accuracy of the information than participants in the non-comparative control condition (i.e., participants who received a message that referenced only "adults"). However, the racial comparison frame had negligible effects on other measures of believability (e.g., agreement that the message is credible, counterarguments to the message), emotions, attributions of responsibility, or policy support, relative to the non-comparative frame. Similarly, relative to the non-comparative frame, the geographic comparison frame decreased the perceived credibility of the message and increased message counterarguing, which was associated with less support for obesity prevention policies.

Social comparison vs. progress and impact frames

Some studies compared the effects of information presented using a social comparison frame to information presented using a progress frame (Nicholson et al., 2008; Landrine and Corral, 2015; Langford et al., 2017; Lee et al., 2017). A few studies also included comparisons to information presented using an impact frame (Nicholson et al., 2008; Uhrig et al., 2013).

Landrine and Corral (2015) examined reactions to mock news articles about colon cancer and found that within the group at higher risk (i.e., blacks), exposure to social comparison-framed articles did not increase perceived cancer risk or intention to get screened as compared with exposure to an article using a progress frame, which emphasized a decrease in colon cancer death rates in the black community. Uhrig et al. (2013) compared messages about STD disparities that used a social comparison frame (blacks affected by gonorrhea at higher rates than whites), a progress frame (gonorrhea among blacks has declined over past decade), or an impact frame (gonorrhea affects blacks at a high rate). The progress-framed message was most effective in terms of emotional reaction (less upsetting, more encouraging), and the impact-framed message was most effective in motivating participants to want to get tested for STDs and to talk to family and friends about getting tested.

Langford et al. (2017) compared the effects of a social comparison-framed message ("African Americans die from chronic diseases like diabetes at a much higher rate than whites") with a progress-framed message ("African Americans are increasing their exercise levels") on willingness to participate

TABLE 2 | Overview of studies testing message framing effects.

Study	Health topic(s)	Study population	Message frames compared	Framing effects
Bannatyne and Abel (2015)	Anorexia nervosa	University students (76% female)	Four etiological (i.e., causal) frames: • Biology/genetics • Sociocultural factors (media influence, body image ideals) • Environmental factors (sporting pressure, modeling of diet behaviors, trauma) • Multiple factors (interaction between biological, societal, and environmental factors)	**Perceptions about responsibility** Multifactorial condition increased perceptions that individuals were responsible for their condition compared with the biological/genetic and environmental conditions Multifactorial and sociocultural conditions increased perceptions that individuals were to blame for their condition compared with the other conditions
Bigman (2014)	Sexually transmitted infections (STIs)	Black, white	Study 1: • Social comparison • Impact (black or white risk only) • Non-comparative	**Risk perceptions** Social comparison frame did not increase perceived risk for the more at-risk group (blacks) compared with impact (black risk only) or non-comparative frames Social comparison frame produced lower perceived risk for less at-risk group (whites) compared with impact (white risk only) frame
	Skin cancer (incidence)	Black, white	Study 2: • Social comparison • Impact (black or white risk only) • Non-comparative	**Risk perceptions** Social comparison frame did not increase perceived risk for more at-risk group (whites) compared with impact (white risk only) and non-comparative frames Social comparison frame produced lower perceived risk for less at-risk group (blacks) compared with impact (black risk only) and non-comparative frames
	Skin cancer (survival)	Black, white	Study 3: • Social comparison • Impact (black or white risk only) • Non-comparative	**Risk perceptions** Impact (white risk only) and non-comparative frames produced higher perceived risk for less at-risk group (whites) compared with the social comparison frame Social comparison frame produced higher perceived risk for the higher-risk group (blacks) compared with impact (white risk only) and non-comparative frames
Dunham et al. (2016)	HIV/AIDS Diabetes	Black, white	• Social comparison • Individual responsibility • Non-comparative/does not emphasize individual responsibility (control)	**Risk perceptions** **Among blacks:** No difference in risk perceptions between social comparison and non-comparative frames (HIV and diabetes) Risk perceptions were higher in combined social comparison and individual responsibility frame than control (diabetes) **Among whites:** Risk perceptions were lower in individual responsibility frame than control (HIV) Risk perceptions were higher in individual responsibility frame and combined social comparison/individual responsibility frame conditions than control (diabetes) **Perceived credibility** **Among blacks:** Lower level of trust in information for individual responsibility frame compared with control (HIV) **Among whites:** Higher level of trust in information in social comparison frame than control (HIV and diabetes) Lower level of trust in information in individual responsibility frame than control (HIV)

(Continued)

TABLE 2 | Continued

Study	Health topic(s)	Study population	Message frames compared	Framing effects
Frederick et al. (2016)	Overweight and obesity	Consisted of university students and participants recruited from Mechanical Turk	• Individual responsibility • Outside of one's control	**Risk perceptions** Individual responsibility frame increased perceptions of the risks of being overweight/obese compared with other frame **Other effects** Individual responsibility frame produced greater belief that weight is controllable, more support for charging obese people more for health insurance, more prejudice against overweight people, more willingness to discriminate against overweight people, and less willingness to celebrate body size diversity compared with other frame
Jones et al. (2016)	Cardiovascular disease risk	Black	• Social comparison + neutral health topics • Neutral health topics	**Behavior** Social comparison frame reduced task persistence (completing a health self-assessment)
Landrine and Corral (2015)	Colon cancer	Black	• Social comparison • Non-comparative	**Risk perceptions** No difference in perceived cancer risk **Behavioral intentions/behavior** No difference in intention to get screened for colon cancer or to recommend screening for family **Emotional reactions** Social comparison frame produced more negative response (insulted, discouraged, angry, suspicious) compared with non-comparative frame
Langford et al. (2017)	Diabetes	Black	• Social comparison • Progress	**Behavioral intentions** No difference in intention to participate in diabetes prevention study
Lee et al. (2017)	General health problems, HIV, and smoking	LGBT	• Social comparison • Progress • Impact	**Emotional reactions** More negative responses (discouraged, insulted, and angry) to social comparison frame than progress and impact frames More positive responses (hopeful, feel good, proud, inspired and encouraged) to progress frame than social comparison or impact frames **Perceived credibility** Higher perceptions of message credibility in progress condition than social comparison or impact conditions
Nicholson et al. (2008)	Colorectal Cancer	Black	• Social comparison • Impact • Progress	**Behavioral intentions** Progress frame produced increased desire to be screened compared with impact or social comparison frames **Emotional reactions** Progress frame produced more positive response compared with impact or social comparison frames Social comparison frame produced more negative response compared with impact or progress frames
Skurka (2019)	Obesity	Recruited through Mechanical Turk (82% white, 10% black)	• Social comparison (racial comparison) • Social comparison (geographic comparison) • Non-comparative	**Emotional reactions** No difference in responses (sympathy, anger) between the racial comparison frame or geographic comparison frame and the control **Perceived credibility** Higher acceptance of the accuracy of the information in the racial comparison compared with the control condition. No difference between the racial comparison frame and control on other measures of believability (agreement that the message is credible, counterarguing the message), attributions of responsibility, or policy support Lower perceived credibility of the message and increased message counterarguing in geographic comparison compared with control condition

(Continued)

TABLE 2 | Continued

Study	Health topic(s)	Study population	Message frames compared	Framing effects
Uhrig et al. (2013)	STD (gonorrhea)	Black	• Social comparison • Progress • Impact	**Risk perceptions** Social comparison and impact frames generated greater agreement with the statement "Gonorrhea rates are high among African Americans" than the progress frame **Behavioral intentions/behavior** Impact frame more likely than other frames to motivate participants to want to get tested for STDs and to talk to family and friends about getting tested **Emotional reactions** Progress frame less upsetting and more encouraging than other frames **Perceived credibility** Trust in information higher in impact than social comparison condition

in a diabetes prevention and physical activity study and found that message framing had no effect on blacks' willingness to participate in the study. However, this study did not assess the effects of framing on risk perceptions, emotional reactions, or behavior.

Etiological or causal framing

People often have preexisting beliefs about cause and responsibility for a health condition that can vary by race, gender, income, and age (Brady, 2016). These beliefs about cause and responsibility can be influenced by the way a message is framed. Etiological framing can influence perceptions of responsibility and support for policies to reduce health disparities (Niederdeppe et al., 2008). For example, one study compared the effects of four frames addressing varied causes of anorexia nervosa and found that how the message was framed influenced beliefs about the cause of the condition (Bannatyne and Abel, 2015). The condition was framed as being caused by either biology/genetics, sociocultural factors (e.g., media influence, body image ideals), environmental factors (e.g., sporting pressure, modeling of diet behaviors, trauma), or multiple factors (i.e., the interaction between biological, societal, and environmental factors). Participants who received the biological/genetic frame were more likely to attribute the cause to biology and genetics, those who received the sociocultural frame were more likely to attribute the cause to sociocultural factors, and so on. However, the frames also generated some unexpected effects. Participants in the sociocultural and multiple factors conditions believed individuals to be more responsible and blameworthy for their condition than participants in the other conditions. The authors concluded that attributing the cause to biology and genetics may decrease the level of blame and stigma associated with the condition because biology and genetics are factors over which people have no control.

A common etiological frame used in public health messaging is the individual responsibility frame, which emphasizes factors over which individuals have control, such as behaviors that may increase one's risk of acquiring or developing a disease or health condition (Guttman and Salmon, 2004; Dunham et al., 2016; Lee and An, 2016). A content analysis of video and print PSAs on a variety of health topics found that 80% used an individual responsibility frame (Coleman and Hatley Major, 2014).

A series of experiments examined message framing in mock news articles about being overweight or obese, comparing an individual responsibility frame (i.e., they described being overweight or obese as controllable and inherently unhealthy, and stigmatization and discrimination as acceptable) to a multiple factors frame (i.e., they described being overweight or obese as uncontrollable and not inherently unhealthy, and stigmatization and discrimination as unacceptable; Frederick et al., 2016). These descriptions were based on frames commonly used in news articles about obesity. The researchers found that participants who read articles using an individual responsibility frame expressed more belief in the health risks of being overweight, more belief that weight is controllable, more support for charging obese people more for health insurance, more prejudice against being overweight, more willingness to discriminate against overweight people, and less willingness to celebrate body size diversity. However, they found little or no effect of the individual responsibility frame on support for public policies.

Dunham et al. (2016) found no effect of the individual responsibility frame in messages about HIV and diabetes on risk perceptions, emotional responses, or support for public policy compared with other frames. This study also hypothesized that a combined individual responsibility and social comparison frame would induce denial among the group at higher risk (i.e., blacks) and reduce risk perceptions. Contrary to this hypothesis, a diabetes message using the combined social comparison/individual responsibility frame significantly increased perceived risk among blacks as compared with the control condition. However, an HIV message using this framing did not significantly influence perceived risk among blacks.

Potential Unintended Adverse Effects of Messages Communicating About Health Disparities

Messages about health disparities can have unintended adverse effects both in the short and long term and at the individual and societal levels. The Institute of Medicine (2002) and others have argued that consideration of unintended adverse effects and other ethical issues in health communication is imperative for both moral (i.e., adhering to ethical principles) and practical (i.e., producing the desired impact) reasons. Messages need to balance the potential benefits of presenting health disparities information to raise awareness and promote behavior change with the potential harms, such as stereotyping and stigmatization (Institute of Medicine, 2002; Guttman and Salmon, 2004; Coleman and Hatley Major, 2014; Keller et al., 2014). For example, while targeting is used to increase the relevance of messages to a priority audience, presenting information that links a particular high-risk group with a negative health condition (i.e., highlighting health disparities) can stigmatize the priority audience (Guttman and Salmon, 2004; Friedman et al.'s, 2014) and cause them to perceive messages as reinforcing stereotypes (Sorhaindo et al., 2016). Next, we discuss literature addressing our second RQ on the potential unintended adverse effects of communicating about health disparities, including stigmatization and stereotyping, victim blaming, negative emotional reactions, mistrust of health information, and boomerang effects.

Stigmatization and Stereotyping

In stigmatization, certain attributes become associated with negative evaluations and stereotypes that are well-known in a community or culture and become the basis for excluding or avoiding members of the stereotyped group (Major and O'Brien, 2005). Health messages can inadvertently stigmatize and stereotype people based on their health-related behaviors (e.g., smoking, sexual behavior) or health condition (e.g., HIV). These effects are not benign, as they can affect the identity of individuals and groups and influence the way people perceive themselves and how they are perceived by others (Guttman and Salmon, 2004; Guttman, 2017). Stigmatized individuals may be feared, avoided, regarded as de*via*nt, or blamed for their health condition.

Messages that use a social comparison frame can activate a stereotype threat response in individuals exposed to the message, a phenomenon in which these individuals perceive that they are at risk of confirming negative stereotypes about their group (Cho and Salmon, 2007; Inzlicht and Schmader, 2011; Lee et al., 2017). Stereotype threat is the resulting sense that one might be judged in terms of negative stereotypes about one's group instead of on personal merit. Researchers hypothesize that stereotype threat can adversely affect the attitudes, intentions, and behaviors of the stereotyped group (Inzlicht and Schmader, 2011).

Evidence of these types of unintended effects include anti-tobacco campaigns that stigmatize smokers and people with smoking-related illnesses (Bayer, 2008; Riley et al., 2017). Patients with lung cancer report feeling stigmatized because of the association with a behavior (smoking) that is perceived to be personally controllable (Chambers et al., 2012; Shen et al., 2016). Lung cancer stigma is associated with negative psychosocial and medical outcomes, including delayed diagnosis, poor quality of life, and poor patient-provider communication (Riley et al., 2017). Additionally, PSAs addressing eating disorders can lead to more negative attitudes and less willingness to interact with individuals with this health condition (Iles et al., 2016, 2017).

In the context of HIV, research suggests that messages about pre-exposure prophylaxis (PrEP) may contribute to stereotypes and stigma associated with PrEP users (Thomann et al., 2018). For example, in focus groups with MSM and transgender women, some participants expressed negative views of those who use PrEP. Participants suggested that their perceptions of who would benefit from PrEP were derived from PrEP marketing campaigns. They described messages about the benefits of PrEP as contributing to the stereotype that those who use PrEP engage in condomless sex with multiple partners (Thomann et al., 2018). Many participants also said that this negative stereotype and associated stigma influenced willingness to use PrEP.

Populations at higher risk for a stigmatized health condition may oppose health communication interventions that present disparities information because of concern about stigmatization and stereotyping (Friedman et al.'s, 2014; Drumhiller et al., 2018). A qualitative study with blacks explored perceptions of STD disparities in the black community and found that participants were reluctant to have STD-related disparities information disseminated to non-black communities. Participants expressed concern that the information would stigmatize blacks, perpetuating racism, and discrimination (Friedman et al.'s, 2014).

Priming stereotypes

Another way in which health messages can perpetuate stereotyping is through the process of priming, which can then influence how people are perceived and the judgments made about them (Power et al., 1996; Roskos-Ewoldsen et al., 2009). Priming refers to the automatic activation of representations or associations in memory by exposure to a stimulus, such as a message, which then influences subsequent judgments and behavior (Bargh and Chartrand, 1999; Roskos-Ewoldsen et al., 2009).

Stereotypes can be primed through the personality traits and other characteristics used to describe individuals (Power et al., 1996; Wang, 2019). Depicting individuals in a small number of stereotypical roles or personality types can prime stereotypes and communicate a message quickly, but can also perpetuate those stereotypes (Wang, 2019). On the basis of a study of stigma and counter-stigma frames, cues, and exemplifications in news coverage of depression, Wang (2019) advised that the use of exemplars (i.e., illustrative cases) can be problematic. Stereotypical exemplars can bias judgment and lead to erroneous generalizations.

Public health messages often use visual images to capture attention, reflect the priority audience, and increase perceptions of the message's relevance. However, visual images can prime stereotypes about race, gender, or other group identities (Guttman and Salmon, 2004; Coleman and Hatley Major, 2014;

Young et al., 2016). Examples include portraying blacks as athletes and women as mothers. Stereotypes can also be primed *via* cues in the image (e.g., the setting); by emphasizing norms frequently associated with a group or culture, and by music; such as the use of hip-hop in an advertisement targeting a black audience. A content analysis of PSAs on various health topics found that racial and cultural stereotyping primes were present twice as often in visual images than in words (7 and 3%, respectively) (Coleman and Hatley Major, 2014). The content analysis also found blacks were disproportionately represented in HIV-related PSAs; more than half (52.5%) of these PSAs featured blacks.

In a study that tested message concepts for a Centers for Disease Control and Prevention (CDC) HIV testing campaign, black women found a message concept, which was designed to promote HIV testing among black women, to be offensive. They noted that the image called for "women from all walks of life" to get tested, yet the image depicted only black women (Uhrig et al., 2017). Similarly, Drumhiller et al. (2018) examined receptivity to HIV testing campaign messages and found that the participants (black and Hispanic/Latino MSM) objected to images of gay men perceived to be stereotypical (e.g., flamboyant, excessively feminine). The participants reported that stereotypical images of gay men and cues such as the location of campaign materials in "at-risk" neighborhoods made them feel stigmatized because of their race and sexual identity. Images can also influence estimates of rates of disease for specific racial or ethnic groups. In one study, the inclusion of a photograph of a person from a specific racial or ethnic group led to higher estimates of disease risk for that group, even though the text provided no information about the relative risk of disease by race or ethnicity (Gibson and Zillmann, 2000).

Research has consistently found that people tend to remember visual images better than words, referred to as the "picture superiority effect" (McBride and Anne Dosher, 2002). Consequently, the use of images to support frames and the potential for images to prime stereotypes or to promote stigmatization should be carefully scrutinized (Coleman and Hatley Major, 2014). One study that provides support for this conclusion showed participants messages with stigmatizing images of overweight people or non-stigmatizing images and text that emphasized individual or social determinants of obesity (Young et al., 2016). The results revealed a stronger effect of images compared to text. Stigmatizing images influenced behavioral intention among normal-weight participants, even when the text pointed to social determinants. The researchers suggested that the stigmatizing images may have primed an avoidance response in normal-weight participants such that they shifted their behavioral intentions to avoid the stigmatized condition. However, message condition had no effect on the behavioral intentions of overweight participants. The study did not measure emotional response, so it is unknown whether the stigmatizing messages elicited negative emotion or reinforced self-stigma in overweight or obese individuals.

Stereotypic portrayals can influence perceptions about responsibility (Power et al., 1996). One study tested the effects of stereotypic and counter-stereotypic portrayals of blacks and women on attributions or responsibility and perceptions of credibility (Power et al., 1996). The results showed that negative stereotypic portrayals of blacks resulted in more internal or personal attributions of responsibility in subsequent judgments made about blacks. In contrast, positive counter-stereotypic portrayals generated more external or situational attributions of responsibility in subsequent judgments. Stereotypic portrayals of women decreased the perceived credibility of women, whereas counter-stereotypic portrayals increased perceptions of women's credibility. Similarly, another study found that an article depicting suicidal individuals as outgroup members by describing them in stereotypic terms (e.g., insane, unemployed, juvenile delinquents) generated more stigma than an article describing suicidal individuals as ingroup members (e.g., anyone; Lee and An, 2016).

Victim Blaming

Health messages framed in terms of individual responsibility can result in victim blaming—identifying the cause of the health problem as being the result of an individual's behavior without recognition of social and environmental forces (Institute of Medicine, 2002; Guttman and Salmon, 2004; Cho and Salmon, 2007; Coleman and Hatley Major, 2014; Riley et al., 2017). Linking health with personal responsibility may, by implication, characterize individuals who do not adopt recommended health behaviors as weak or irresponsible. People may react to these types of messages with feelings of guilt, shame, or frustration when they feel they cannot adopt the recommended health behaviors.

In addition to the potential negative emotional effects of presenting information about health disparities using an individual responsibility frame, this frame frequently does not impart a complete understanding of the causes of a disease or condition. In some cases, individual behavior may not actually be responsible for the existence of a disparity. For instance, a disparity in the rate of HIV infection among black MSM compared with other MSM is not the result of black MSM engaging in risky sexual behaviors at higher rates than MSM generally (Matthews et al., 2016). Instead, the disparity in HIV infection rates is the result of a variety of complex, interrelated factors (McCree et al., 2017).

Negative Emotional Reactions

Messages sometimes use negative emotion (e.g., fear, guilt) to communicate a health risk associated with a particular group or identity (Coleman and Hatley Major, 2014; Fairchild et al., 2015). Examples include New York City's fear-based tobacco, obesity, and HIV health communication campaigns (Fairchild et al., 2015). An analysis of PSAs on health topics found that the use of negative emotion was the second-most common frame used in PSAs—present in 48% of the sample—after individual responsibility (Coleman and Hatley Major, 2014).

Social comparison framing can elicit counterproductive negative emotional reactions among the population at higher risk. Several studies compared emotional reactions to messages presented using a social comparison frame as compared with other frames. Uhrig et al. (2013) found that communicating about disparities in STD rates among blacks using a social comparison frame was more upsetting and less encouraging relative to using either a progress or impact frame. In another study, blacks exposed to mock news articles about disparities in colon cancer using a social comparison frame (blacks are doing worse than whites) experienced more negative emotional reactions than those exposed to articles using a progress frame (blacks are improving over time) or impact frame (colon cancer strikes blacks at a high rate) (Nicholson et al., 2008). Landrine and Corral (2015) also examined emotional reactions to news articles about disparities in colon cancer and found that blacks exposed to a social comparison frame felt more insulted, discouraged, and angry compared with those exposed to a progress frame.

Lee et al. (2017) examined the effects of messaging about health disparities in the lesbian, gay, bisexual, and transgender (LGBT) community. Participants exposed to the message presented using a social comparison frame reported that it made them feel discouraged, insulted, angry, and significantly less likely to indicate pride in their LGBT identity, relative to the progress-framed message (Lee et al., 2017). When study participants (black men and women) were informed about racial disparities in STD rates in their community within the context of a qualitative study, they often reacted with surprise, sadness, fear, and despair (Friedman et al.'s, 2014).

Mistrust of Health Information

Social comparison framing may increase distrust of health information among the population at higher risk. This is an important concern given the prevalence of medical mistrust among racial and ethnic minorities, which has been found to influence attitudes and behaviors related to HIV prevention and treatment (Bogart et al., 2010; Mimiaga et al., 2016; Cahill et al., 2017; Thomann et al., 2018). For example, among black men, mistrust of PrEP is a barrier to use (Cahill et al., 2017; Thomann et al., 2018), and belief in conspiracy theories about antiretroviral therapy is related to treatment non-adherence (Bogart et al., 2010).

Several studies found that social comparison framing was associated with higher distrust, compared with other types of framing. In one study, blacks exposed to news articles about disparities in cancer risk, using a social comparison frame, had more doubts about the veracity of the articles (i.e., they were more likely to agree with the statement, "I wonder if it's true. I am suspicious of the story"), compared with those exposed to non-comparative articles (Landrine and Corral, 2015). Lee et al. (2017) found that study participants exposed to a message using a social comparison frame ("With rates double that of the population, smoking poses a deadly threat to the LGBT community") or impact frame ("Half of black gay men will get HIV in their lifetime") had lower agreement with the statement "I believe the message" than those exposed to a message using a progress frame ("LGBT communities are working to address health problems").

Dunham's study (Dunham et al., 2016) of HIV and diabetes messages found that blacks were significantly *less* likely to trust the accuracy of "government data" about racial disparities in HIV prevalence when the information was presented with an individual responsibility frame relative to a non-comparative frame (control group). Conversely, white participants were significantly *more* likely to trust "government data" when presented with a social comparison frame. The findings were mixed for effects of the individual responsibility frame on white participants; this frame significantly decreased trust in the HIV message but significantly increased trust in the diabetes message.

Friedman et al.'s qualitative study (Landrine and Corral, 2015) of perceptions of STD disparities among blacks found that although most participants believed the information, some were skeptical. These participants questioned the objectivity of data sources, suggested the government may inflate or fabricate rates to encourage people to get tested, or disbelieved the lower rates of STDs reported for other racial groups.

Boomerang Effects

A well-recognized unintended consequence of health communication messages is the boomerang effect, which refers to health messages having an effect opposite of the intended effect (Cho and Salmon, 2007). For example, obesity-related messages perceived as stigmatizing have been found to result in increased calorie consumption and decreased motivation to lose weight (Schvey et al., 2011; Puhl et al., 2013; Major et al., 2014; Young et al., 2016).

Health disparities information may have a boomerang effect if the group at higher risk avoids, devalues, or rejects the information. People may not believe, or may view as prejudiced, information threatening their self-concept or favorable image of their group. Social comparison-framed messages about cancer disparities can have this type of unintended effect (Nicholson et al., 2008). Blacks exposed to mock news articles about colorectal cancer mortality experienced more negative reactions to articles using a social comparison frame compared with those exposed to articles using a progress frame or impact frame, and they were less likely to have screening intentions. Medical mistrust moderated this effect, with the progress-framed articles producing higher intentions to get screened than the social comparison-framed articles among participants with a high level of mistrust. Participants with a low level of mistrust did not differ in terms of their screening intentions across conditions.

DISCUSSION

Based on our review of the broader body of literature addressing the effects of messages about health disparities, we developed a conceptual framework that presents potential positive and negative effects of communication about HIV-related disparities (see **Figure 1**). Although we hypothesize responses to messages about health disparities to be similar across health contexts, this model will need to be tested empirically in the context of HIV. Next, we discuss implications of the literature that we reviewed and offer recommendations for communicating about HIV-related disparities based on the available evidence. We conclude by proposing a research agenda to fill gaps in the evidence base regarding effective strategies for communicating about disparities across the HIV continuum.

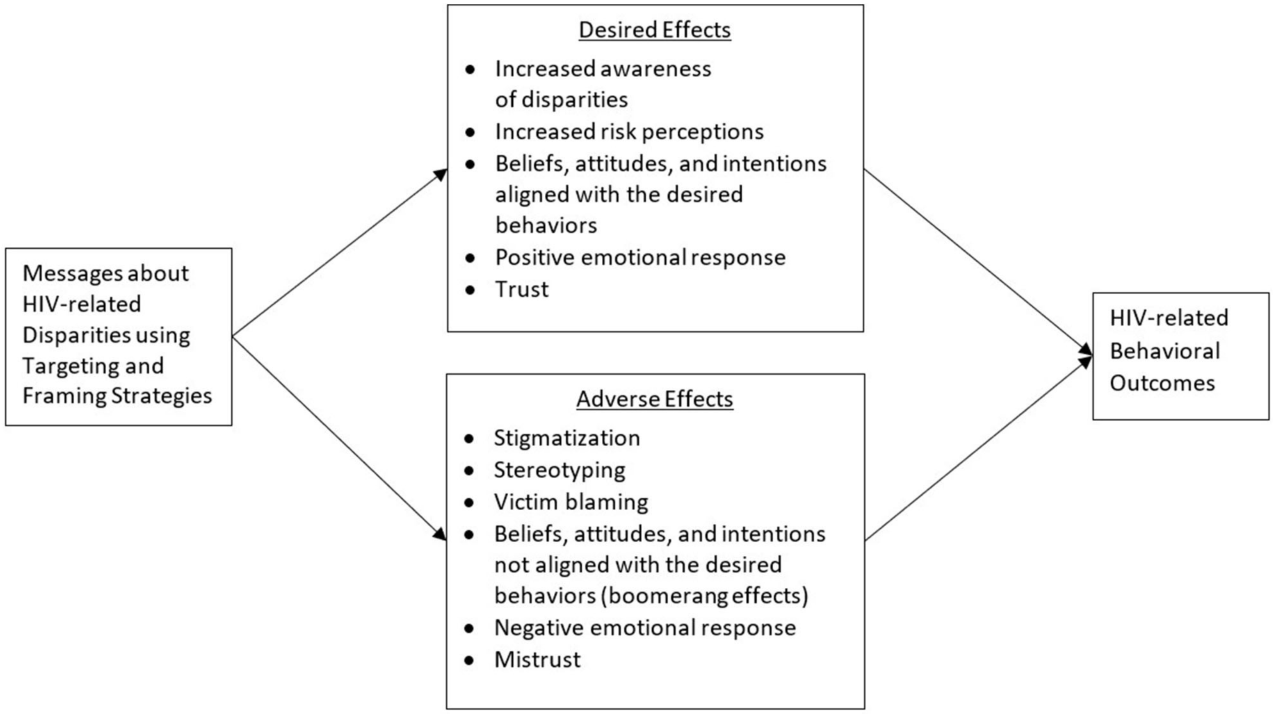

FIGURE 1 | Positive and negative effects of communication about HIV-related disparities.

The goal of this literature review was to identify promising approaches for effectively communicating about health disparities across the HIV care continuum. Given our RQs, we specifically intended to examine strategies used to communicate health disparities and investigate potential unintended adverse effects of messages communicating health disparities to identify how specific message strategies contribute to the unintended effects. We found limited literature specifically addressing the RQs in the context of HIV. Although there is a substantial body of literature on communication interventions that address HIV (e.g., Noar et al., 2009), the body of research focused on examining the effects of messages communicating HIV-related disparities within and outside priority audiences is limited. There are likely multiple explanations for why this body of research is not more developed. One possible explanation may be that focusing on social determinants of health and the social and environmental processes and inequities that contribute to health disparities is still relatively recent in the U.S. (Braveman and Gottlieb, 2014). Increasing attention to these factors has recently contributed to the interest in providing higher-risk groups with more context to help them better understand underlying reasons for the disparities. Additionally, disparities in HIV-related outcomes between some groups, such as blacks and whites, have continued to increase (Allgood et al., 2016). Recent research has also begun to highlight a growing concern that messages about HIV-disparities may have unintended effects (e.g., Lee et al., 2017; Thomann et al., 2018). Thus, the aim to increase awareness of these disparities while avoiding unintended effects has become more crucial over time.

A common strategy for communicating about health disparities is to use a social comparison frame, which compares the differences in rates of disease or outcomes between a group more at risk and a group less at risk. Although this is an intuitive strategy for attempting to increase risk perceptions within a priority audience, which is an important predictor of health behavior, studies often find that a social comparison frame does not increase risk perceptions in the group more at risk (Bigman, 2014; Landrine and Corral, 2015; Dunham et al., 2016). Additionally, the evidence points to several potential adverse consequences that can occur with social comparison framing, including stigmatization and stereotyping, negative emotional reactions, and distrust of the information (Landrine and Corral, 2015; Lee et al., 2017).

When considering including direct comparisons between racial or other subgroups, as is often done in messages that communicate health disparities, it is important to understand how social psychological processes might influence message effects. Social comparison-framed messages can be perceived as a threat to one's group and individual identity. Social identity theory provides a framework for understanding the relationship between social comparison and intergroup processes (Tajfel, 1982). For a group that suffers from a lower status in society, direct comparisons with a higher-status group can have negative psychological consequences, such as devaluing one's group, engaging in self-hate, and expressing preferences for the outgroup. Alternatively, because people are motivated to maintain a positive social identity and self-image, for members of the lower-status group, social comparisons can also result in attributing the cause of the discrepancy to external factors that are outside of one's control and can generate greater ingroup/outgroup distinctions and ingroup favoritism. Social comparisons also can increase outgroup bias (i.e., negative evaluations of outgroup members) among members of the higher-status group. It is easy to see how these responses are counterproductive to the goals of messages designed to communicate about health disparities and can have detrimental individual and societal effects.

Another framing strategy, the individual responsibility frame, addresses health disparities by emphasizing the role of individuals in both increasing and reducing their risk. This approach can generate negative emotional responses, reinforce stigma, and result in distrust of the information (Dunham et al., 2016). It also places the responsibility for health disparities on the individual, when this is often not accurate (Matthews et al., 2016). Another challenge with this frame is that people have preexisting beliefs about groups and health risks that can influence how they process and respond to messages (Brady, 2016; Calabrese et al., 2016; Thomann et al., 2018). For example, research in social psychology has identified biases in how social information is processed. One such bias, known as the fundamental attribution error, reflects a tendency when making causal judgments to overestimate the influence of personal factors and underestimate the influence of environmental factors (Ross, 1977). Consequently, messages that focus on individual responsibility as a causal explanation for health disparities serve to reinforce rather than challenge psychological biases.

Communicating about health disparities also has the potential to prime stereotypes *via* the use of a variety of visual and textual cues. Visual images are particularly influential, and they have the potential to overpower text, reinforce stereotypes, and perpetuate stigma (McBride and Anne Dosher, 2002; Coleman and Hatley Major, 2014; Young et al., 2016; Uhrig et al., 2017).

Thus, messages about health disparities share many of the characteristics that Smith (2007) described as being present in messages that communicate stigma. They draw attention to distinct groups of people defined by racial, social, or behavioral characteristics; they link these groups to a physical threat (i.e., HIV or another health condition); and by using either a comparative or individual responsibility frame, or in some cases both, they suggest indirectly or directly that group members are responsible for the threat. Although the intention behind messages about health disparities is to increase awareness and motivate positive behavior change, the characteristics of these messages can instead generate unintended effects for both the unstigmatized group—including social distancing, negative attitudes, and support for stricter policies—and the stigmatized group.

Unintended effects—such as negative emotional reactions, decreased trust in health information, perceptions of blame, and stereotyping—can cause members of the priority audience to distance themselves from and reject messages about health disparities. Rather than reducing risk and improving health outcomes, these messages can worsen health if they backfire and can also have negative psychological consequences for members of the priority audience. These potential iatrogenic effects are especially important to consider when communicating about HIV-related disparities, as the same groups that experience disparities across the HIV care continuum also experience intersectional stigma (Earnshaw et al., 2013; Rice et al., 2018), which could be further exacerbated by the way disparities information is communicated. In addition, medical mistrust among racial and ethnic minorities has been found to influence attitudes and behaviors related to HIV prevention and treatment (Bogart et al., 2010, 2011; Cahill et al., 2017; Thomann et al., 2018), and this mistrust could also be perpetuated by the framing of disparities information. As such, messages need to balance the potential benefits of communicating HIV disparities to raise awareness and promote behavior change with the potential harms that may result from the framing (Institute of Medicine, 2002).

It is also critical to ensure that members of priority audiences are involved in message development, pretesting, and implementation of communications. Involving members of the priority audience in these activities is best practice in public health communication. However, it also serves to empower communities that face systemic inequities and foster collective action to reduce disparities and improve health outcomes (Douglas et al., 2016; Thompson et al., 2016). Messages and communications that address health disparities with the intention of fostering individual and community empowerment can shift the focus from individual blame to a fuller understanding of the multi-level factors that contribute to

TABLE 3 | Recommendations for communicating about HIV disparities.

- ✓ Use progress framing and appeals that evoke positive emotions that motivate action (e.g., hope, encouragement, positive roles) rather than messages that evoke sadness and can be demotivating (Lazarus, 1991; Nicholson et al., 2008; Friedman et al.'s, 2014; Landrine and Corral, 2015; Frederick et al., 2016).
- ✓ Address distrust in disparities information by ensuring data are transparent and presented credibly (Nicholson et al., 2008). For example, include verifiable sources of information, such as a publicly accessible website, and information about data collection and how rates are derived.
- ✓ Recognize social and societal factors that contribute to HIV disparities while also motivating individuals to "take charge" (e.g., adopt specific behaviors) by including a strong efficacy message regarding what actions individuals have the power to take (Lundell et al., 2013; Friedman et al.'s, 2014). It may also be useful to take a social justice approach within messages, focusing on resiliency—at both the individual and community levels—as a means to address disparities (Matthews et al., 2016).
- ✓ Use images and exemplars strategically to avoid reinforcing stereotypes (Coleman and Hatley Major, 2014). Pretest images with members of the target audience to ensure they are not offensive (Uhrig et al., 2017).
- ✓ Carefully consider the use of cultural symbols and themes (Institute of Medicine, 2002). When developing messages, ask the following:
  - Will the use of cultural themes stereotype the population?
  - Are there individuals or groups that may be excluded or stigmatized when cultural themes are a dominant part of the communication intervention?
  - Are cultural symbols or themes used in a message relevant to the advocated behavior (as identified through formative research), or do they represent outside perceptions of what may be valued or familiar to the audience (i.e., stereotypes)?

TABLE 4 | Agenda for future research on communicating about HIV disparities.

Research activity	Rationale
Experimentally compare messages about HIV-related disparities across the continuum of care using progress, impact, and social comparison frames.	Social comparison-framed messages about health disparities do not always increase risk perceptions in the target audience (Bigman, 2014; Landrine and Corral, 2015; Dunham et al., 2016) and can have adverse effects, including stigmatization and stereotyping, negative emotional reactions, and distrust of the information (Landrine and Corral, 2015; Lee et al., 2017). Additionally, only one previous study compared framing strategies in the context of HIV (Dunham et al., 2016). Thus, it would be beneficial to examine whether frames other than a social comparison frame can increase risk perceptions without having adverse effects.
Experimentally test message strategies that acknowledge the multiple factors (i.e., social determinants) that contribute to HIV risk and may be outside of an individual's control, while also acknowledging the role of the individual in reducing risk.	Challenges that emerge from the literature on health disparities messages are that (1) messages that discuss the contribution of social determinants of health may not address individual behavior and thus may not motivate health behavior change (Lundell et al., 2013), and (2) messages that address individual health behavior alone may be perceived as stigmatizing and can perpetuate misunderstanding about the cause of a disparity (Matthews et al., 2016). Thus, it would be useful to investigate whether messages that discuss both social/societal and individual factors reduce negative responses to messages while also motivating behavior change. This is a type of mixed or competitive frame that tends to be overlooked in research on message framing effects (Guenther et al., 2020).
Assess how images and exemplars can be incorporated in HIV disparities messages to increase personal relevance, attention, and persuasiveness without reinforcing disparities related stereotypes. Studies can evaluate different combinations of images, exemplars, and text to assess emotional response and effects on risk perceptions and other outcomes.	Exemplars and images can prime stereotypes and bias judgment (Guttman and Salmon, 2004; Coleman and Hatley Major, 2014; Arpan et al., 2017). Visual images within health messages tend to be more influential than text; although they are often used to increase message relevance, they can be also perceived as stereotypical and offensive by members of the target audience (Uhrig et al., 2017; Drumhiller et al., 2018).
Examine how anti-stigma communication approaches found to be effective in reducing mental health stigma may be used in HIV communication interventions.	Meta-analyses of mental health anti-stigma communication research found that approaches that facilitate interpersonal or "mediated" contact successfully reduced stigma associated with mental illness (Corrigan et al., 2012, 2015). Creative approaches are needed to develop opportunities for "contact" with people with HIV and to evaluate effects on audiences. One way of mediating contact with stigmatized groups is by using photovoice, an approach used to counter stereotypes, external stigma, and internal stigma (Wang et al., 2000; Russinova et al., 2014; Centers for Disease Control and Prevention (CDC), 2019). Although these studies suggest some promise, this approach has not been tested in combination with framing or in the context of HIV.
Examine whether messages about HIV disparities designed to elicit positive emotions such as encouragement and hope—similar to progress-framed messages—are effective in motivating positive behavior change.	According to functional theories of emotion in psychology, emotions are elicited in response to our environment and motivate action in ways that are consistent with personal goals (Lazarus, 1991). This perspective on emotion suggests that the response to shame, which is associated with stigma and the perception that one is being stereotyped, is to hide and avoid facing what may be perceived by oneself or others as personal failure (Lazarus, 1991). As this is not the desired response to health risk messages, other approaches need to be investigated. Two studies that tested responses to skin cancer prevention messages found that hope was positively associated with self-efficacy perceptions and that hope and self-efficacy predicted intentions to engage in skin cancer prevention behaviors (Nabi and Myrick, 2019).
Investigate whether integrating self-affirmation with health risk messages about HIV disparities will be effective in promoting positive behavior change.	Messages that present information about health disparities can be perceived as threatening to one's social identity (Tajfel, 1979). Previous research found that engaging in a self-affirmation exercise before exposure to a threatening health message can reaffirm one's self-concept, thus increasing message acceptance and positive health behavior change (Epton and Harris, 2008). A recent study found that a health risk message that incorporated self-affirming text in the message produced greater intentions to reduce risky behaviors (Arpan et al., 2017).
Examine whether messages focused on fostering individual and community empowerment will increase trust and be more effective in generating positive individual- and community-level responses to reduce HIV disparities.	Messages about health disparities can be perceived as blaming individuals for poor health outcomes, which can produce a multitude of adverse effects and make messages ineffective or, worse, harmful. Incorporating community members and their feedback into message development and campaign implementation can increase the likelihood that these interventions will be effective (Earnshaw et al., 2013). It can also increase the capacity of messages and communication campaigns to empower individuals and communities to engage in positive behaviors and actions that reduce health disparities (Douglas et al., 2016; Thompson et al., 2016).

health disparities (Douglas et al., 2016). This approach also has the potential to lead to more effective messages and interventions by increasing trust and credibility among the priority audience (Earnshaw et al., 2013).

Recommendations and Agenda for Future Research

Applying the available evidence on message framing to HIV, we offer recommendations for communicating about HIV-related disparities, presented in **Table 3**.

Some evidence suggests that using a progress frame to present health disparities information may be more likely to generate positive emotional and behavioral responses than using a social comparison frame (Nicholson et al., 2008; Landrine and Corral, 2015; Lee et al., 2017). However, the evidence comprises only a handful of studies—some of which compared only a progress frame with a social comparison frame—and even though the progress frame performed better, the extent of its positive effect is unclear. In addition, none of the studies were specific to HIV. Other approaches to message framing, such as using an impact frame, may also be effective for communicating about HIV-related disparities (Uhrig et al., 2013). Furthermore, it is unclear which message framing strategy is most effective when communicating about HIV-related disparities to the general public vs. targeting messages to subpopulations at high risk for getting or transmitting HIV.

Due to the limitations in the existing body of evidence, we propose a research agenda to examine strategies for effectively communicating about HIV-related disparities, while avoiding unintended effects (**Table 4**).

CONCLUSION

Health communication can play an important role in reducing HIV-related disparities and stigma, which is a central priority of *Ending the HIV Epidemic: A Plan for America* (U.S. Department of Health and Human Services, 2020). Further efforts are needed to develop and test communication strategies capable of raising awareness of, influencing attitudes and beliefs about, and motivating behavior change necessary to reduce HIV-related disparities without resulting in stigmatization or other unintended adverse effects.

AUTHOR CONTRIBUTIONS

All authors made substantial contributions to the conception or design of the work, the acquisition, analysis or interpretation of data for the work, drafting the work or revising it critically for important intellectual content, provide approval for publication of the content, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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frontiers in Communication

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"They Just Went After Us:" Reproductive Justice Advocacy at an Abortion Fund

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In this study, I explore how organizers at an abortion fund use new media to create communication outreach about abortion and their hotline service. The data for this study includes 1 year of digital ethnographic work as a hotline volunteer at the abortion fund, along with in-depth interviews with the fund's advocacy team. The fund organizers want to appeal to supporters, protect and empower communities, confront systemic oppression, and dispel medically incorrect, neoliberal (i.e., racist, sexist, and classist) anti-abortion myths. Due to societal stigma and silence, public abortion discourse is largely shaped by media (mis)representation. To combat misinformation and misogyny, reproductive justice (RJ) organizers disrupt mainstream abortion narratives with their own outreach. The organizers in this study use social media to interact with the public, supporters, donors, and anti-abortion activists alike. While these organizers publish anonymous data and stories from their hotline on social media, they also vigorously protect the privacy of their callers and hotline volunteers. The organizers recognize the importance of callers seeing their experiences represented in public discourse while also feeling protected from anti-abortion backlash. Therefore, I argue the abortion fund organizers carrying out this digital advocacy work are engaging in multifaceted emotional labor and putting their bodies on the line for a stigmatized issue. This study is informed by research that speaks to the promises and perils of new media for community building, movement organizing, and what Molina-Guzmán (2010) calls "symbolic rupture." Social movement organizers work within the shifting media environment to transform cultural narratives, build solidarity, sustain their organizations, fundraise, and stand on the front line of stigmatized issues—even while enduring the consequences of personal exposure.

Keywords: new media, health activism, abortion, stigma, reproductive justice (RJ), emotional labor

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INTRODUCTION

On a Sunday morning in May 2009, while acting as an usher in the foyer of his church in Wichita, Kansas, Dr. George Tiller was shot in the head and killed. At the time of his death, he was 67 years old, and had already survived a previous assassination attempt as well as the firebombing of his abortion clinic (Stumpe and Davey, 2009). Dr. Tiller's murder is a famous example of anti-abortion violence, but it is not unique. In October 1998, Dr. Barnett Slepian returned from synagogue and was shot through his kitchen window by a sniper. He died in front of his family (Fletcher, 1998). Earlier that year, the bombing of an abortion clinic in Birmingham, Alabama, left an off-duty police officer dead and a clinic nurse gravely wounded (Sack, 1998). In 2001, a self-described "anti-abortion terrorist" sent over 550 letters containing graphic death threats and white powder (an anthrax hoax) to abortion clinics across the United States (Associated Press, 2003). In 2015, a gunman killed three people in the parking lot of a Planned Parenthood in Colorado Springs (Paul et al., 2015). In 2019, an anti-abortion protestor backed his car into a 65-year-old volunteer clinic escort in Alabama, seriously injuring her (Johnson, 2019).

Since 1977, the National Abortion Federation (NAF) has documented 11 murders, 26 attempted murders, 42 bombings, 188 arsons, and thousands of other criminal acts committed against U.S. abortion providers and clinics (National Abortion Federation, 2019). In 2018, the NAF also identified record-breaking numbers of trespassing, obstruction, and picketing incidents at clinics (National Abortion Federation, 2019). The violent expression of anti-abortion sentiment is a complex psychological issue. However, media (mis)representations of abortion can normalize rage as an acceptable response to abortion's existence. Media (mis)respresentations of abortion also perpetuate medical misinformation and demonize people who seek abortion care. Sisson and Kimport (2017) find abortion misrepresentation is rampant in mainstream media. For example, media narratives largely underrepresent the financial and legal barriers faced by many seeking reproductive healthcare, which can lead the public to doubt the existence or formidability of these obstacles. When media narratives do include abortions, the safe, routine procedures are regularly depicted as violent, sudden, or physically dangerous.

In response to media misrepresentation, poor societal understanding of women's health, and sometimes-violent anti-abortion rage, reproductive justice (RJ) organizations are working to combat stigma and misinformation in order to protect abortion and other reproductive healthcare. One feminist organization doing this RJ advocacy work is the Althea Fund[1]. The Althea Fund is an abortion fund in Texas that runs a hotline to help pregnant people access funding for their abortion procedures. Fundraising and funding hotline callers are the primary objectives of the hotline. However, when trained hotline volunteers speak with callers and ask voluntary demographic questions, they gather data from callers that is anonymized and added to already collected aggregate data. This data documents on the ground lived experiences with systemic inequity, providing a realistic picture of abortions and the people who seek them. Through outreach that includes snapshots of this aggregate data (e.g., "A majority of our callers are already parenting"), Althea organizers work to end abortion stigma, garner support for the RJ movement, and raise money for their hotline.

These "true stories" and facts about abortion care and access are persuasive, but due to abortion stigma, Althea organizers are not willing to ask already marginalized and precarious callers to share their names or faces. Therefore, the organizers take anonymized hotline data and personally walk out into the (largely digital) public sphere—facing interpersonal conflict, societal outrage, and even death threats head on. Thus, I argue Althea organizers put their own minds and bodies on the line for the movement as they take on exposure and engage in multifaceted emotional labor on behalf of abortion access. I find Althea organizers to be an interesting case study, as they essentially act as digital "stand ins" for their vulnerable callers and marginalized people in the public sphere. This means when anti-abortion sentiment or rage flares up, it is often directed at highly visible individuals like these organizers. The internet and 24-h news cycle are *always* on, so there is *always* a chance that organizers will feel a buzz and look down to see someone asking for help, seeking political commentary, or overtly threatening them.

To contextualize Althea organizers' efforts, I first describe mainstream media representations of abortion. Next, I discuss the possibilities and perils of participatory new media as a potential tool for healthcare advocacy and mobilizing counter-publics. In particular, I discuss how RJ movement advocates have used new media to combat stigma, stereotyping, and medical misinformation. Finally, I turn to interview and observation data from Althea organizers who, at the time of interviewing, acted as the face of the organization and interacted with various publics to defend abortion access. I describe how Althea organizers grappled with best practices for using their own names and faces to lessen abortion stigma, create compelling RJ-centered messages, and convince people to donate.

METHODS

The data in this study was gathered across 1-year and over 100 h of ethnographic participant-observation as a volunteer at the Althea Fund. During that year, I tried to adhere to self-reflexive feminist research values. Sprague (2016) also argues that, for feminist researchers, "understanding how things work is not enough" (p. 3). With that, I attempted to do ethnographic work that helped further the Althea mission in tangible ways. My efforts included taking weekly shifts to return calls as a hotline volunteer, listening to voicemails and logging the calls, traveling to participate at in-person advocacy events, and providing simple data analysis and visualization for board meetings.

Throughout my research, I recorded, transcribed, and thematically analyzed over 25 h of phone and video interview material with 22 Althea organizers and volunteers. All of this data and experience informs this study. However, for the purposes of this paper, I attend primarily to expansive interviews with two Althea leaders. While the organization has grown and added outreach and advocacy staff, these two leaders were personally managing the organization's outreach at the time of interviewing.

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[1] This data was collected with Institutional Review Board (IRB) approval, as well as approval from the abortion fund organization. The names of the organization, organizers, and volunteers have been changed to protect privacy. The IRB at Texas A&M University waived the need for written consent. Verbal informed consent, including for the reproduction of their verbatim quotations was obtained from the participants before the interview.

MEDIA, POLICY, AND ANTI-ABORTION LANGUAGE

Banet-Weiser and Gray (2009) suggest mediated "representations structure and construct the cultural meanings of identities, practices, and systems of power" (p. 14). The Althea Fund's communication outreach exists within a public context saturated with meaning constructed and shaped by media. Media representation is especially important when considering stigmatized issues like abortion that are rarely discussed openly in interpersonal conversations. Because abortion is not discussed in "polite conversation" or even public sex education, mainstream media becomes a "particularly powerful and prominent" source of public understanding and opinion about the issue (Jaworski, 2009, p. 105). Though it is difficult to directly correlate public opinion with media consumption, Jaworski (2009) calls for researchers and activists to pay attention to how mainstream media narratives depict reproductive healthcare (p. 117). Language and narratives about abortion in healthcare policy, news media, and fictional stories continue to influence societal and individual understanding of abortion procedures, experiences, and accessibility.

Anti-abortion Sentiment and Abortion Stigma

To understand how mainstream media embodies anti-abortion sentiment, we must first understand the values underlying neoliberal and neoconservative anti-abortion rhetoric. Neoliberalism in the United States is not unique, as researchers have studied the effects of similar ideologies in the United Kingdom, Canada, and beyond (McGregor, 2001). This Western, globalized ideology is rooted in beliefs of achieved equality, commercialized diversity, and individual excellence (Brown, 2006; Gray, 2015). Ideas emphasized in neoliberalism are choice, accountability, and merit, all at the individual level (Lipman and Hursh, 2007, p. 162). Duggan (2003) states neoliberalism was "constructed in and through cultural and identity politics," co-opting antiracist and feminist movements and suggesting their goals had been achieved (p. 3). Neoliberalism is an ideology of "post" realities that suggests the United States is a postracial and postfeminist society with equitable individual opportunity for all. In this "post" society, Gray (2015) says "consumer friendly discourses of multiculturalism and diversity replace historic concerns about the lack of cultural parity" (p. 1108). Because everyone is said to have equitable opportunity, systemic inequality "takes shape as a political norm rather than a political challenge" (Brown, 2006, p. 708).

While neoliberalism is an ideology that is neutral, market-based, and amoral at its core, in the United States it exists in tandem with the neoconservative ideology. Neoconservatism consists of moral governance practices that rest on neoliberal constructions. While neoliberalism is a "secular faith" (Duggan, 2003, p. XIII), Brown (2006) describes neoconservatism as an "unevenly and opportunistically religious" ideology that has laid the groundwork for authoritarianism to work alongside an intense focus on the individual (p. 696). A belief in the neoliberal, moral self as hardworking, self-made, righteous, and deserving means the existence of permanently poor, "criminal," or otherwise struggling people can be seen as the natural and "inevitable cost" of virtuosity being rewarded (Brown, 2006, p. 695). As Duggan (2003) writes, financially and socially rewarding only the "virtuous" class enables "attacks on downwardly redistributive social movements," like the Black Lives Matter or reproductive justice movements (p. XII).

Even in healthcare, where pregnancies or medical complications can be difficult or impossible to prepare for or address until they arise, neoliberalism transforms care issues into "individual problems with market solutions" (Brown, 2006, p. 704). Though the neoliberal ideology touts empowerment, it "produces citizens as individual entrepreneurs and consumers whose moral autonomy is measured by their capacity for 'self-care'—their ability to provide for their own needs" (Brown, 2006, p. 694).

Women are citizens who have particularly had their human rights jeopardized by market forces, neoliberal individualism, and patriarchal neoconservative norms. Though women in countries like the U.S. have achieved "formal" gestures of equality, such as the right to vote, inequality continues through "occupational segregation," the gendered work-pay gap, and the "double burden of unpaid care work and wage earning" (Smith, 2008, p. 131). Briggs (2012) notes that abortion in particular has long been tied to "narratives of fault, punishment, and personal responsibility," which are gendered narratives usually associated with the pregnant person (p. 23). Pregnant people who need access to abortion services are typically deemed "irresponsible," made to seem selfish, and often shamed into silence (Kennedy, 2001, p. 164).

Goffman (1963) explains that feelings of shame and stigma come from not meeting societal "demands." In society, Goffman (1963) suggests, "we lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands" (p. 2). People who experience shame and feel stigmatized perceive they have been "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Abortion is readily understood in U.S. society as a tainted act. Abortion stigma, then, is a "negative attribute ascribed to women who seek to terminate a pregnancy that marks them, internally or externally, as inferior to ideals of womanhood" (Kumar et al., 2009, p. 4). Inferior members of the "bad girls tribe," then, are seen as "deserving stigma because of their own personal failings" (Cockrill and Nack, 2013, p. 975). Feelings or expectations of abortion stigma typically lead people to believe hiding their abortion experience(s) is the only acceptable path forward. In the United States, United Kingdom, Mexico, Nigeria, Pakistan, Peru and beyond, studies have documented the connection between abortion and stigma, self-judgment, isolation, and concerns for secrecy in both people who have abortions and people who help provide abortion care or access (Shellenberg et al., 2011; Astbury-Ward et al., 2012; Cockrill et al., 2013; Hanschmidt et al., 2016).

Abortion stigma at times still comes from "pro-choice" advocates, as even people who believe in bodily autonomy can still strongly believe in personal irresponsibility and failure (Cockrill and Nack, 2013, p. 981). However, anti-abortion labels of "murderer" and "killer" tend to be more intense and aggressively silencing. Anti-abortion imagery has traditionally been more visceral than pro-choice imagery. As Hayden (2009) describes, the "significance of fetal imagery for the articulation of <life> cannot be overstated" (p. 114). Anti-abortion activists use the word murder and, at times, grotesque imagery.

Fetal imagery and calls of murder can lead to normalized rage and, in extreme cases, the violent actions described at the start of the paper. Mainstream abortion narratives regularly discuss and reflect shame, stigma, and silence, which RJ organizations seek to combat. Through understanding anti-abortion sentiment, we can see "the influence of political opponents and social detractors on movement ideology" (McCaffrey and Keys, 2000, p. 41). That is to say, popular anti-abortion sentiment dictates what RJ activists must respond to and normalizes the violent or other threats they endure.

Abortion Stigma in Public Health Policy

Importantly, the language used in media coverage of abortion draws upon (and feeds back into) healthcare policy. Sun-Hee Park (1998) argues explicit language in public policy is important, as the attitudes and beliefs espoused through proposed polices "have the power to affect the everyday lives of individuals" through perpetuating stigma, taboo, and shame—regardless if the law is passed or not (p. 193). The language used in reproductive healthcare policy affects the public psyche and can serve to silence or scare individuals who have received or might seek abortion care.

There are many documented examples of policies that include language attempting to intensify or silence abortion discourse. In 2004, the U.S. House of Representatives created the Unborn Victims of Violence Act, in which they shifted federal policy away from using the term "fetus" and instead used "unborn children" in their prenatal language (Unborn Victims of Violence Act, 2004). Similarly, in December 2017, *The Washington Post* broke a story that alleged Center for Disease Control officials had effectively "banned" seven words from being used in CDC documents for the upcoming budget (Sun and Eilperin, 2017). The list of words notably included the term "fetus," suggesting other words should be used in the place of this term.

In Texas's 2017 Senate Bill 8, policymakers repeatedly used the term "dismemberment abortion" to describe a common abortion procedure. "Dismemberment" is not a term used or recognized by medical professionals in relation to the procedure (Texas LegiScan, 2017). In the same year, proposed Texas House Bill 948 suggested women and providers should be charged with murder if an abortion procedure was performed. The lawmaker behind the bill stated knowing there would be "repercussions" would force women to be "more personally responsible" (Guarecuco, 2017). In 2018, expansive coverage of "heartbeat bills" and other policies debated across multiple state legislatures continued to stoke confusion, anger, and fear. When policymakers write non-medical, violent, or emotionally charged language into proposed laws, they insure those words media coverage in the public sphere.

Media Coverage of Abortion

Ferree (2002) documents that public abortion discourse in the United States went through a "century of silence" from about 1890 until 1950 (p. 25). With the signing of *Roe v. Wade,* abortion reemerged in U.S. public discourse as a polarized, stigmatized, and misunderstood issue relegated mostly to mediated depictions rather than meaningful conversations (Ferree, 2002; Hayden, 2009). Data from a 2015 research survey showed that nearly 70% of participants "reported that 'media' was the most popular source of abortion information" in their personal lives—far outweighing discussions with their family members, in educational spaces, or with people who have had abortions (Conti and Cahill, 2017, p. 429). While abortions are a common procedure (it is estimated that one in four U.S. women will have an abortion in their lifetime), there continues to be relative stigma and silence around personal experiences with abortion. Media narratives fill this silence. Reproductive justice researchers and advocates know "media frequently use negative language and framing when covering abortion, and that such frames work to produce abortion stigma" (Sisson et al., 2017, p. 395).

When media coverage perpetuates scary, shameful abortion discourse, it can serve to silence meaningful discussion about abortion. In their creation of content, then, journalists and other media creators have the ability to help provide opportunities for more robust and humane discourse. Yet, both Conti and Cahill (2017) and Sisson et al. (2017) describe how journalists find it difficult to accurately depict abortion experiences and medical opinions due to false equivalency norms in reporting. These norms suggest journalists have to appear unbiased and present all sides of an issue "even if one side is scientifically false or based on no evidence at all" (Conti and Cahill, 2017, p. 427). Furthermore, Sisson et al. (2017) found 80% of the journalists they interviewed who report on abortion access with a "progressive" stance have faced harassment and even threats from readers and viewers.

While journalists try to retain their jobs and stay safe, news media continues to decenter the public health aspect of abortion and normalize a polarized framing of the issue. As Hernández and de Los Santos Upton (2018) carefully document, popular conservative news outlets frame abortion as "divisive" and often "remove women and women's bodies from the abortion context altogether" unless referring to "botched abortions" or other graphic imagery (p. 33).

While anti-abortion language, neoliberal framing, and misinformation permeate healthcare policies and subsequent news coverage, ideally the realm of fictional media could offer a space to portray accurate information and humanizing narratives. There are several recent examples of film and television media that normalize abortion. In 2014, actor Jenny Slate and writer and director Gillian Robespierre created the film *Obvious Child*, which follows a young female comedian who decides to have an abortion after an initial one-night stand (Holm and Robespierre, 2014). Film critics and the president of Planned Parenthood praised the film's depiction of abortion as a normal choice and safe, common procedure (Kermode, 2014; Richards, 2014).

The 2019 television series *Shrill*—created by and starring comedian Aidy Bryant—includes an abortion-positive narrative in its first episode. Bryant's character, Annie, goes to Planned Parenthood to have what appears to be a common aspiration abortion procedure. Annie holds her roommate Fran's hand for support as the physician explains the process aloud. The physician describes how she is numbing and opening Annie's cervix, reminding her that "light cramping" is normal. Then, a few days later, when Fran asks Annie how she is, Annie responds with a grin, "I feel really, really good … I don't know. I feel very fucking powerful right now" (Bryant et al., 2019).

Some abortion providers and activists have hailed *Obvious Child* and *Shrill* as celebrating autonomy and depicting abortion with heartfelt, honest sensitivity. Yet, these narratives still center young, white characters who are not parenting, which is not the primary demographic that seeks abortion care. The narratives also do not explicitly include financial and other obstacles to abortion access. However, the new HBO film, *Unpregnant,* and a recent short film, *Lucia, Before and After*, do depict some of these obstacles. *Lucia* won the 2017 Sundance Film Festival Short Film Jury Award. This 13-min film shows how a young woman, Lucia, in west Texas spends the 24 h mandated waiting period between her ultrasound consultation and abortion procedure (Nadig and Valia, 2016). Lucia drives several hours to the clinic, has her ultrasound, and then, without extra money to spend, runs out of a bar unable able to pay for her meal and sleeps in her car while trying to pass the time before her abortion. *Lucia* shows a glimpse of some of the realistic challenges a pregnant person might navigate to access abortion care.

Outside of rare examples like these, however, medically and otherwise inaccurate depictions of abortion permeate fictional media. As Sisson and Kimport (2017) remind us, "television representations of all aspects of life, including different areas of medical care, often depart from reality for the sake of a good story" (p. 57). The issue of abortion is no exception. In recent fictional television and film abortion narratives, Conti and Cahill (2017) culled several striking research findings. For example, 37.5% of characters who obtained an abortion experienced a complication or negative health effect, when the actual aggregate risk is 2.1% (Conti and Cahill, 2017, p. 428). In addition, onscreen depictions of deaths due to abortion occurred in 5% of plotlines, which is "about 7,000 times the actual mortality rate" of practically zero (p. 428). Moreover, characters obtaining abortions were "disproportionately white, young, wealthy, and not parenting" in media depictions (Conti and Cahill, 2017, p. 428). In addition to these findings, Sisson and Kimport (2017) note that only 4% of all fictional abortion-related stories show a character meeting an "insurmountable" obstacle, which stops them from obtaining the procedure. This underrepresentation of systemic barriers to access suggests abortion and general reproductive healthcare is more easily accessible than in reality. These misrepresentations bolster a neoliberal, individualistic framework in which any person who chooses to have an abortion can readily access the procedure and make their decision based on (selfish) individual desire.

With depictions of abortion across news and entertainment media continuing to spread misinformation and perpetuate neoliberal myths, RJ movement media outreach acts as a response. In an ideal world, these activists' advocacy would help shift dominant narratives and public policy to be more medically accurate, inclusive, and humane.

NEW MEDIA FOR SOCIAL JUSTICE

Though Banet-Weiser and Gray (2009) posit media in "the contemporary era continues to be influenced by expert knowledge holders who act as gatekeepers," they also echo others (Jenkins, 2006; Chun, 2009) who assert that new, interactive, and increasingly accessible media and technologies are challenging traditional gatekeeping (p. 15). It is true that many people still get their information through mainstream media and pay attention to dominant discourse to make sense of the world (Downey and Fenton, 2003; Costanza-Chock, 2014). Still, as we have seen with campaigns like Black Lives Matter, new media can elevate a social movement to mainstream discourse and widespread media coverage.

Furthermore, it is through the media we consume and create that we "relate to, visualize, and recognize each other" and ourselves (Chun, 2009, p. 9). In a time when most people's daily interactions with media revolve around "rapid forms of production and circulation enabled by new, mobile, miniature technologies of production and circulation," there is potential for new ways of understanding ourselves, others, cultural norms, and stigmatized issues to emerge (Banet-Weiser and Gray, 2009, p. 15).

By connecting like-minded individuals and activists, new media's collective intelligence becomes a form of power for social movements to harness (Jenkins, 2006, p. 4). Molina-Guzmán (2010) describes the possibility for digital users to create "symbolic rupture," or "disrupt the process of symbolic colonization" in mainstream representations of their own lives and experiences (p. 9). New media users can discuss and circulate what Hall (1993) would call oppositional readings of dominant narratives to produce symbolic rupture.

Using new media, creators and activists can offer new narratives and counter stereotypes. When people encounter multiple narratives, simplistic understandings of issues and groups becomes more difficult to maintain. As Ramasubramanian (2011) documented in her study on white students and media exposure, "exposure to a few counter-stereotypical media exemplars can bring about a definite shift in racial attitudes" (Ramasubramanian, 2011, p. 14). Other studies have shown similar results, with exposure to counter narratives and diverse media representation positively influencing viewers' understanding of and emotions about stereotypical groups and issues (Power et al., 1996; Ramasubramanian, 2007; Ramasubramanian and Oliver, 2007; Holt, 2013).

Thus, new media's capacity for rupturing dominant narratives is important for social movements. Rohlinger (2002) writes that social movement organizations and organizers are no longer "simply the objects of media coverage," but rather "reflexive agents that interact with the structures of media" and use new media strategically to influence public discourse (p. 483). Costanza-Chock (2014) echoes this sentiment, noting how "over the course of the last 20 years, widespread changes in our communications system have deeply altered the relationship between social movements and the media" (p. 2). In their 7-year experience as a movement ally in transmedia immigrant rights activism, Costanza-Chock (2014) found social movements use the shifting media ecology to "build movement identity, mobilize people for action, shift cultural narratives, and advance policy goals" (p. 181).

In healthcare movements in particular, Gillett's (2003) analysis of HIV/AIDS patients' use of social media for self-representation is one example of research documenting new media's potentials for health activism (Zoller, 2005; Berridge, 2007; Moorhead et al., 2013). Furthermore, in Dehlendorf and Rinehart's (2010) review of health communication research, they cited the work of over 20 studies as evidence that using media and other resources to encourage "discussion of reproductive issues" individually and societally has led to demonstrated beneficial outcomes on both levels (p. 324). More specifically, new media and "internet-based health interventions" are considered "low in cost and resources, convenient for users, help to overcome feelings of isolation, reduce stigma, and involve substantial user control over the intervention" (Upadhyay et al., 2010, p. 419).

New Media Advocacy in the Reproductive Justice Movement

Reproductive justice, like most contemporary movements, uses the internet, new media, and technology prolifically. Importantly, though I will focus on RJ movement media, the internet is a space for everyone to gather and exchange (mis)information—including anti-abortion activists and organizations. While I document strategies and successes of RJ new media in this paper, viral anti-abortion sentiment is also part of the often-manipulative online context of social media. So, while they are regularly met with threats and well-organized virtual anti-abortion sentiment, Althea Fund and other RJ organizations use new media to counteract mainstream narratives and influence social attitudes about abortion (Rohlinger, 2002, p. 483). Movement supporters, the public, and people in need of abortion care are all potential audiences for RJ movement outreach. When constructing messages, McCaffrey and Keys (2000) maintain RJ organizers should be concerned with both establishing the "legitimacy of the movement" while also mobilizing their supporters (p. 44).

One instance of new media swiftly mobilizing support in the RJ movement was the use of Twitter during Wendy Davis's famous 11-h filibuster in the Texas Senate to oppose the anti-abortion bill, HB2, in 2013. While nearly half of all tweets with hashtags such as #StandWithWendy and #StandWithTXWomen came from Texas GPS locations, the rest of the Twitter support came from regions including "the West coast, the Mid-Atlantic, the Midwest, and the coastal North East" (Stevenson, 2014, p. 504). While people were physically in the Texas capitol watching Senators Wendy Davis and Leticia Van de Putte speak out against the bill, hundreds of thousands more were tuning in and engaging in real-time with the filibuster livestream online. Online consciousness-raising through hashtags creates discourse that "bridge[s] gender issues in the public and digital spheres" (Lane, 2015, p. 5). The use of new media to organize and mobilize supporters is important for demonstrating loud, vocal support for abortion and other stigmatized issues (Costanza-Chock, 2014; Conti and Cahill, 2017).

However, as detailed above, abortion stigma is strong in U.S. public discourse. In this context, RJ movement organizers try to create space for people to speak safely about their personal abortion experiences. In particular, pro-choice abortion speak-outs have allowed individuals who were ashamed or scared to break their silence about their abortion experiences. Abortion speak-outs have a long history in women's rights activism. As many have described, speak-outs have typically been organized spaces in which people could share their abortion stories (Shulman, 1980; Salmon and Neuwirth, 1990; Ross, 1993, Dubriwny, 2005). Ideally, individuals speaking about their abortions could help break the "spiral of silence" around the issue (Salmon and Neuwirth, 1990). In turn, speak-outs as a consciousness-raising practice can improve individual and collective understandings of abortion obstacles, policy, procedures, and experiences (Dubriwny, 2005).

Yet, speaking out about abortion might be more closely aligned with a pro-choice rather than reproductive justice movement, particularly if the "speaking out" does not acknowledge the complexity of reproductive oppression and violence. Reproductive justice, as defined by *SisterSong Women of Color Reproductive Health Collective*, includes "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities." (Reproductive Justice, 2018). Loretta J. Ross (1993), a founder of *SisterSong* and the RJ movement, tells us we must listen to Black and marginalized women's voices in order to comprehend how abortion access is embedded in systemic (neoliberal) inequity (p. 141). The voices of women of color begin to illuminate the sexist, racist, classist, and other oppressive forces underpinning this inequity. Crenshaw (1991) famously explained how the intersection(s) of structural, political, and representational forces further subjugate and marginalize women of color. With that, the experiences of wealthy white women seeking abortions will likely not be as fraught as the experiences of poor Latina migrant women in California seeking prenatal care (Zavella, 2016), and yet intersectional reproductive justice encompasses both circumstances. Fregoso (2014) might call this "decolonizing human rights," or moving away from "the liberal doctrine of human rights codified in law" toward the "collectivist politics of social justice activists" (p. 586). Generally, we describe this expansive, collectivist approach as *intersectional*.

In current new media RJ activism, *We Testify* (https://wetestify.org/) exists as an intersectional digital space for documenting and circulating personal abortion stories. *We Testify* is an online platform for "abortion storytellers" to share their experiences. Storytellers can accompany their story with their name and photo, or they can use a pseudonym or tell the story anonymously. By posting on *We Testify*, storytellers "demand to be counted" in public discourse (Testify, 2017). The site and organization behind it aim to shift "the way the media understands the context and complexity of accessing abortion care" (About, 2017).

Cristina, the executive director at the Althea Fund and former *We Testify* contributor, described *We Testify* as a "storytelling cohort" that centers narratives from women of color and marginalized people. She commended *We Testify* as a platform for sharing abortion stories that combat the neoliberal narrative. Cristina told me:

> [They are] a great example of storytellers who use real stories and voices of people who have had abortions to change the narratives, to be upfront, and to center their experiences. As opposed to, like, this "good" abortion, or exceptional or moral *blah blah blah* examples. It's great. The majority of people who receive abortions are women of color, and [*We Testify*] is women of color run and centers women of color. That's the kind of shifting I think we need in the movement and they're in the thick of that.

As Cristina highlighted, *We Testify* focuses on stories shared from people "of color, those from rural and conservative communities, those who are queer identified, those with varying abilities and citizenship statuses, and those who needed support when navigating barriers while accessing abortion care" (About, 2017). In doing this, the platform aims to challenge dominant (mis)understandings of abortion and abortion access, shifting the conversation from "choice" toward "largely inaccessible human right."

If an organization like *We Testify* can create successful outreach, "they can expand the debate around an issue, energize a movement by mobilizing a population, and increase movement and organizational legitimacy in the political sphere" (Rohlinger, 2002, p. 479). McCaffrey and Keys (2000) elaborate on the importance of establishing public credibility as it is "a crucial commodity for movement organizations because it translates into influence;" the media creator who possesses "the greatest degree of credibility has the power to define the issues and the bounds of the debate" (p. 56). Furthermore, Cockrill and Nack (2013) argue "increasing social contact between people with abortion experiences and people without abortion experiences may be one of the most important elements for changing social attitudes," which can include not only social media from people who have personally had abortions but also people who have intimately provided abortion services or access (p. 987). There is a healthy infrastructure of RJ advocacy organizations and new media initiatives, and direct service organizations like the Althea Fund and clinics rely on these efforts to continue generating credibility for the RJ movement in public discourse.

COMMUNICATION OUTREACH AT THE ALTHEA FUND

Even as they rely on storytelling and other large organizations (e.g., Planned Parenthood, the ACLU, NARAL) for movement legitimacy, the Althea Fund also creates outreach in order to promote and sustain their organization. Riya, the then-president of the Althea Fund, explained that communication outreach, while not the centerpiece, is essential to the organization. When discussing RJ organizations, Riya felt "people see [the Althea Fund] as one that has an anti-oppression voice and one that talks about our work in a way that is meaningful to them." Riya contributed Althea's success and longevity to the continuous outreach efforts of the organization and its members. Moreover, outreach is the primary means through which the Althea Fund solicits donations. Because Althea leadership recognized the positive impact of consistent outreach, these efforts were highly valued and carefully crafted.

Though volunteers largely run the hotline, Althea leadership intentionally limits organizational outreach labor to a small team of organizers. Not only does this help streamline the labor, as there are fewer voices and opinions involved, but Althea organizers are seasoned activists who have long done movement work. Ideally, this means outgoing content will remain aligned with intersectional RJ values, but it also presents a challenge in making sure Althea volunteers feel heard. As Riya told me:

> We haven't figured out a good way to get more people involved in communications work, it's been an ongoing challenge. Part of it has to do with how communications works. You have to pay really close attention to detail and be in constant communication with those you're working with. It's not something people can dip in and out of.

Riya's description of Althea outreach labor adheres to the tenets of Rohlinger's (2002) small communications team. These small teams can be more responsive to real-time engagement needs, but they also take on all of the work and personal consequences. The Althea organizers doing this outreach work were consistently interacting online with supporters, donors, and anti-abortion activists alike, readily adjusting their intellectual and emotional responses. They were performing complex emotional labor at all hours of the day.

Hochschild (1983) defines emotional labor as labor that "requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others" (p. 7). As in, your job requires that you actively manage your own emotional expression in order to elicit beneficial emotions—and, hopefully, desired actions—from your customers, clients, or audience. Humphrey et al. (2008) observe that leaders in particular have to be ready to "display a wide variety of emotions, ranging from friendliness, to sympathy and support, to anger" as they interact with employees, clients, and the public as the "face" of their organization (p. 155).

Emotional labor is well documented in abortion access work, due in large part to abortion stigma. Simonds (1995) documented how laborers involved in "abortion work" are regularly "being called upon to demonstrate empathy and nurturance to their clients and with each other, yet at the same time to appear controlled, united, and assertive in the face of the enemy" (p. 255). Furthermore, Wolkomir and Powers (2007) drew on 16 months of participant observation at a women's healthcare clinic to describe how employees detached or invested in various patients in an effort to process their emotional labor and continue to provide abortion care.

However, an important distinction between abortion work and other types of customer service-oriented emotional labor is the sense of purpose abortion access workers might feel.

Wolkomir and Powers (2007) find that, when it comes to abortion care, "people often enter these fields because they believe the work is socially important and are therefore more likely to have heavily invested in the work and infused it with valued self-meanings" (p. 154). If an employee has a job they feel embodies their personal values, it can boost their sense of authenticity and self-efficacy at work. O'Donnell et al. (2011) echo that "for individuals involved in abortion care, abortion is understood not as simply a moral, political, or intellectual discourse, but as a lived experience" (p. 1362). The work of providing and/or paying for abortion is a hands-on experience for all involved. People doing the work do not provide money to someone else to try to fight for reproductive rights, but rather they safeguard and provide someone's access to those rights. Doing abortion work means you feel like you are tangibly helping someone while facing the stigma of doing "dirty work," or work society deems "morally dubious" (Martin et al., 2014a, p. 586). Yet, the "high levels of pride" involved in abortion work can offset the fatigue and negative emotions associated with stigmatized labor. In their study of abortion providers, Martin et al. (2014a) documented these providers "experienced higher than average levels of compassion satisfaction, and lower than average levels of burnout and compassion fatigue" (p. 585). In a separate study of abortion providers, Martin et al. (2014b) found:

> Approximately half of the workers (54%) reported feeling proud to work in abortion care "all of the time," and an additional 29% felt proud "often." Participants also felt their work made a positive contribution to society—84% reported feeling this way "all of the time" or "often" (p. 647).

While abortion stigma can be exhausting to navigate, a sense of pride and purpose can buoy the psyches of abortion workers and lead to less burn out and more resiliency. Yet, though mightily resilient and steadfast, Althea organizers acting as the "face" of the organization had to be prepared at any moment to greet misinformation or open hostility with emotional finesse.

Social Media at the Althea Fund

In his influential book *The Presentation of Self in Everyday Life*, Goffman (1959) suggested people have a public self they curate and show to society, which they try to keep consistent and aligned with their purported values. The same goes for organizations like the Althea Fund, who are mindful of the strained cultural context and careful about intersectional values-alignment. At the Althea Fund, they construct their public image primarily through social media, though they also send email newsletters and maintain a website. The work necessary to maintain Althea's public image is constant digital labor that involves informing and managing multiple publics in an emotionally effective way.

As the only fulltime staff member at the time of interviewing, Cristina spent a lot of time creating and monitoring Althea outreach. She managed the Facebook and Instagram pages, while also writing emails to supporters, which Riya later edited before distribution. Recognizing the power of Twitter to support spontaneous organizing via hashtags, Cristina also took to Twitter "on big days when [the Althea Fund] needs to have a presence." Examples of these "big days" were days when public hearings about anti-abortion bills SB8 and HB214 were scheduled during the 2017 regular and special summer Texas legislature sessions. Outside of live-tweeting major policy and protest events, Cristina told me she would log into the Facebook page to post material "two or three times a day" to inform followers about the RJ movement and keep supporters engaged.

Intersectional Consciousness-Raising and Managing Supporters' Emotions

Many supporters only associate the Althea Fund with abortion, yet Cristina wanted to insure Althea was still associated in intersectional solidarity with reproductive and social justice mutual aid broadly. As will be described below, at times, these intersectional associations jeopardized Althea's fundraising efforts. Yet, Cristina and other Althea organizers did not waver from promoting an intersectional consciousness in their supporters and donors. For example, she posted about statewide organizing for mandatory paid sick days for Texas workers. Cristina used these posts to remind followers that economic inequity leads to reproductive inequity, so labor justice is important to the RJ movement. The Althea Fund and other RJ organizations also post and repost from each other regularly about issues of immigration, queer and trans representation, and the U.S. maternal mortality rate, which is the highest in developed nations (Chuck, 2017).

Intersectional awareness, education, and motivation to act are major themes in Althea content. In creating what is hopefully educational but also persuasive content, I asked Cristina who she envisioned as the audience for her outreach:

> I'm thinking of people who are already with us. I'm not trying to persuade anyone—trying to make someone who is anti-choice pro-choice. I'm thinking of people who have shared values. But I'm also thinking very much of our donors… our main kind of donor is pretty much a grassroots advocate. The majority of our donations are grassroots smaller amounts. We aren't top heavy—we're super bottom heavy. Yes I'm thinking about them as donors, but I'm also thinking of them as grassroots advocates.

Cristina mentioned she was always thinking about fundraising, but it seemed important that she stress the framing of a typical Althea donor as truly "a grassroots advocate" for the movement. Cristina agreed when I pointed this out: "We're trying to validate our base. I'm working hard to activate people who are already on board and just need a little push or need some validation."

Alice, a then-board member for Althea, echoed these sentiments about mobilizing an intersectional RJ movement base. She reflected on how often she interacted with "pro-choice" advocates who were not aware of abortion funds. When trying to fundraise for the Althea Fund, Alice said a "shocking number of people don't understand what abortion funds are." Cristina, Alice, and other organizers found "pro-choice" supporters often took abortion access for granted. As Cristina said, "you hear the saying that people don't think about abortion until they need one." Alice agreed, speaking bluntly about her frustration interacting with people who identify as pro-choice: "People don't realize what the Hyde Amendment is. People don't realize this stuff is not covered. People don't realize how much it costs. I don't think people understand the system of policies and inequities producing the need for abortion funds."

Despite frustrations felt by some Althea organizers at the lack of knowledge about obstacles to abortion access, Cristina acknowledged these supporters were usually ideal targets for Althea communication outreach. When thinking about crafting outreach, Cristina reflected:

> I think there is this sort of this profile of a person. A person who says, "I wouldn't have an abortion, but I'm ok with it. I don't really want it in my face." We reach those folks, too. I would say we do some narrative shifting in that way.

When considering supporter-focused outreach, there was regular discussion at Althea about balancing messages that inspired all supporters, messages that solicited action, and messages that educated about intersectional values. As Cristina and Alice stated above, Althea often catered to supporters and donors who were not fully aware of the myriad social and financial obstacles hindering callers from obtaining safe and legal abortion care. Thus, Althea organizers felt they had to find ways to effectively (yet gently) push back against a lack of structural awareness and intersectional consciousness. If someone holds a more traditional pro-choice stance and is unaware of the many facets of the reproductive justice platform (e.g. anti-capitalist abolitionist trans-inclusive antiracism), Althea organizers suggested their messaging might be alienating or confusing.

Regardless, Althea organizers created messages that stuck to their interpretation of RJ principles. This meant they took the emotional labor necessary to manage criticism from supporters upon themselves. During my year of participant observation, donors regularly expressed concerns about the intersectional RJ platform and its impact on Althea's public image. For example, when police killed Philando Castille and Alton Sterling on back-to-back days in the summer of 2016, the Althea Fund quickly expressed solidarity with the Black Lives Matter movement through a mass email to supporters. Riya described how this email was, at first, received poorly by a major (white male) donor:

> We have an intersectional, antiracist lens. We've had two donors push back—two white male donors. They don't like it for various reasons... they've been major donors. When Philando Castille and Alton Sterling were killed, that same week [we] put out a Black Lives Matter email by [Tiffani, a Black Althea organizer]. She wrote a beautiful piece that we put out. We were really proud of it and then our donor—the most significant family of our donors, they've given more money than anyone else—he wrote to us with an earnest concern, I think. He thought we might do [the Althea Fund] a disservice if we were "straying from our message and starting to talk about other things, we might turn donors off." So what we did is we worked very carefully on drafting a response to him that was like "Look, these are major issues in our clients' lives. This is part of our mission. This is how we're carrying out our mission. And by talking about these issues, we're actually bringing more people into our organization. We're going to be able to do more." I'm very proud because we brought him along with us and he actually continued to donate.

Riya felt Althea Fund leadership was able to successfully diffuse the situation and explain to a donor how and why the Althea Fund is antiracist. By taking time to communicate openly and warmly with the powerful donor about the intersectional nature of oppression, Althea organizers were able to sustain the relationship in a way they felt would not compromise their intersectional principles or disrespect the lived experiences of their callers. This takes carefully executed intellectual and emotional effort, and probably a bit of what Hochschild (1979) calls "surface acting," or a painstaking focus on expressing emotions in a way that does not shift anything deep inside of you but still gets the job done (p. 558).

However, in another instance of donor-pushback, Riya felt the tactic of "calling in, not calling out" was not necessary or useful. The second instance happened in late summer 2017 after Donald Trump had been president for several months:

> This past week, though, we sent out our annual report … Well, we get this nasty email from this donor—this millionaire—who said I have racist views and that I was insulting white people. There's a line in the letter that says: "because the majority of white people voted for Donald Trump." It is a factual statement about how Donald Trump was elected—primarily white people accepted bigotry and other things. Well, he had a huge problem with it and his email was really nasty. We're having our white board members respond to him. They're telling him why this is an issue—since the majority of policies being passed are by white men … It's not a "bring him along" message, because his message was nasty. For people who don't think they are racist but are racist, they're going to have a problem with our message. That's ok, we don't need their support. There are other people who can support us. We're not trying to alienate donors, but we're also not trying to cater to racists. We don't need to compromise our values for support, we have plenty of people who want to support *because* of our values.

In this case, Althea organizers still responded to an emotional outburst, but in a way that did not suggest they were concerned with future engagement. Althea organizers were clear: reproductive justice is antiracist and the Althea Fund is part of that movement. Neoliberal beliefs allow systemic racism to persist as normal, and this normalization has implications for Black and brown Althea callers who seek affordable healthcare. Though the Althea Fund acknowledges and addresses systemic racism regularly, several organizers also told me it is *not* their job to convince white donors that white racist society perpetuates itself. Instead of this powerful donor, Althea organizers chose to preference the emotions of their callers and people they felt need to see themselves and their lived experiences with racism reflected in abortion narratives in order to heal or feel empowered. Though Althea organizers came together and decisively agreed on their response, knowing their actions would likely sever ties with a large donor was difficult and emotionally (and financially) draining.

Importantly, these are only two examples of the many times Althea organizers had to decode, manage, and respond to supporters' emotionality. When people rally around misunderstood or stigmatized issues, support often comes with expectations, judgment, and, in this case, internalized abortion stigma. Althea organizers were well aware of the expectations in abortion discourse. As Cristina mentioned, there are societal and even pro-choice narratives around what constitutes a "good" or acceptable abortion. Through their efforts to call in (rather than call out) pro-choice supporters, Althea leadership worked to expand supporters' understanding of abortion through outreach that felt welcoming and engaging rather than chastising. The organizers' ongoing efforts to interact with donors and supporters in a benevolent yet effective and decisive manner was, at times, exhausting to witness. Althea organizers internally vented exasperation with societal (mis)understanding of intersectional abortion oppression, yet externally communicated openhearted invitations to "join the fight" to end abortion stigma and help individuals seeking abortions access their care in real time.

Undeniably, these individuals' highly personal "real-life" abortion stories are vivid, heart wrenching, and persuasive. "True stories" can illustrate how "undue burdens" operate in the real world and help to disrupt mainstream or choice-specific abortion narratives. Yet, even while sitting on a pile of tantalizing qualitative data, due to abortion stigma, Althea organizers were insistent that care for callers and caller privacy was paramount. A mantra several organizers regularly stated was, "The caller owes us nothing." Therefore, in order to protect callers and further the movement, Althea organizers placed their names and faces next to these nameless facts and faceless "true stories," putting themselves emotionally and sometimes physically on the line to share truth.

Anti-abortion Sentiment and Managing External Threats

While managing communication with Althea supporters and donors seemed stressful, Althea organizer interactions with anti-abortion advocates was much more intense to witness. Because the Althea Fund focuses on protecting callers and hotline volunteers from further harm or abuse in the public sphere, Althea organizers are usually the voices and faces in Althea communication outreach. Being "the face" of the Althea Fund meant looking directly at palpable hostility. In using social media platforms and free technologies from giants like Google, Facebook, and Twitter, Althea organizers, like anyone using new media, "face increased surveillance when they take their activities online" (Costanza-Chock, 2014, p. 8). Not only can the public keep up with the Althea Fund, but so can anti-abortion activists, or "antis" as Althea and other organizers called them.

When I asked Althea organizers about their experiences with external threats due to media exposure, they greeted me with several stories of being targeted and threatened online. The president, Riya, described an incident that happened where she was personally targeted:

> We actually had to lock down [the Althea] Instagram … Our Instagram was public before and there was a picture of me and other board members and I was wearing … this dress that says "Abortion" with hearts all over it. I was wearing it in the picture and some like terrible right-wingers downloaded it from our Instagram and tweeted it all over the place saying really terrible things about us. It was … it was really nasty. We started to realize we had to get some control over that.

Riya told me this story as some Althea organizers had recently started being "more forward" with their names and images. Social media is meant for exposure, and feelings of personal connection can sustain traffic and interaction. Riya wore her dress with intentionality. She was purposefully exposing Althea followers to the word "abortion" being worn by a woman in public without shame. However, as we have all experienced, online content does not always (or ever) remain only on the feeds of our intended audience. When Riya wore a dress as a form of embodied activism in a photo, she became a target for anti-abortion threats and rage—rage normalized through abortion stigma, misinformation, and division.

Due to threats like those Riya received, Riya and Cristina both described the ways in which the Althea Fund was actively considering the emotional and physical safety of any individual connected to their outreach. Riya said:

> If we're going to put out pictures or names, it's generally someone very involved in the organization like a board or staff member. If we have a volunteer that wants to write something for us, it might just be their first name… or if they include their last name, they approve it. We are primarily concerned about our executive director's safety. [Cristina] is the public face of our organization. She's in the news all the time. An anti-choice publication quoted her last year. That is a concern for all of us. I don't know if we've quite figured out what to do with that.

Even though her face was the one most consistently and prominently featured in Althea content, Cristina spent much of our interview talking about ways in which she thought about others' exposure and safety. I also experienced this first hand when I participated at an in-person advocacy event. At the event, there were around 30 of us working in small groups to discuss best practices for RJ advocacy. We then donned t-shirts with the word "Abortion" written repeatedly inside of a heart and walked into the Texas capitol to visit with state representatives about anti-abortion bills that session. There were many individual and group photos taken of participants in our shirts. Cristina gave us all forms listing each individual social media platform where the Althea Fund might share the photos. If you did not sign next to a social media platform, images with your likeness would not be posted on or linked to that site. This was one of many precautions taken by Cristina and other Althea organizers.

When I reminded her about my experience at this event, Cristina began to elaborate on her considerations for her own and others' safety in media exposure:

> I do think about [safety]. If we're at a rally and there's a cute photo of a woman and her kid, I would never post a photo of a kid

> without permission … or pretty much at all on our organization's page. People we don't know, I think about. But our board members, spokespeople, the ambassadors of our organization, that's kind of the job. You're out there, kind of high profile … I mean I guess I'm technically the most high profile. I go in front of the media. There was one documentary done by *The Guardian* where they showed an entire shot of my house. They interviewed me at my house, but some of the B roll was just a shot of my full house. This is my house that I own. Y'all can't be doing that.

Cristina continued to tell me about other times she was featured on various media platforms when she testified at policy hearings, spoke in front of marches, or wrote newspaper op-eds. Time after time, Cristina worked for abortion access, talked openly about a stigmatized issue, and subsequently navigated personal threats and attempts at emotional abuse.

Furthermore, organizers not only faced threats on an individual level, but they also managed threats to the organization. Althea's social media pages sometimes became gathering places for online trolls, or "antis," which at times led to large-scale abuse aimed at the fund. One particularly intense influx of rage on the Althea Facebook page happened after Hurricane Harvey in late August 2017. Althea organizers posted a graphic about how the natural disaster limited already precarious abortion access. The post was meant to boost fundraising efforts. However, a national conservative news organization also found it and quickly circulated it in a story.

On the news organization's Facebook page, they linked their story along with a link to the Althea Fund Facebook page. The organization used quotation marks in their story and headline, seeming to hint at discrediting or ridiculing Althea's mission. For example, there were quotation marks around the word "emergency" when referring to the funds being raised. The accompanying story suggested organizations like the Althea Fund were run by "left-wing activists" who are known for "politicizing tragic events" in the name of their social justice "pet projects." The news organization's Facebook post was reacted to over 40,000 times, with thousands of comments on the post suggesting there is a "special place in hell for these folks" who are "still promoting killing babies" in hurricane-ravaged areas. The comments on the post echoed the title's use of quotation marks, suggesting there could be no "emergency" when it comes to abortion care.

Meanwhile, on the Althea and other abortion fund hotlines, calls were coming in at nearly twice the rate. Clinics were closed for several weeks and all appointments were canceled without rescheduling. This was an emergency for people making abortion pregnancy decisions, with each week that passes bringing higher procedure costs and different procedure expectations. Plus, with varying state restrictions, if a few weeks or days pass, a pregnant person might hit the number of weeks at which abortion becomes illegal for them in that state. This means they would have to spend time and money to travel across state lines.

Nevertheless, the Facebook post and accompanying news stories ended up rousing anti-abortion advocates and crowds to action. The Althea Fund's Facebook page was flooded with aggressive threats and calls for the fund to shut down. Cristina recalled, "They just went after us. We had to shut down comments. We had to block people. We had to be on 24/7 watch. We were getting horrible threats … really violent shit."

Though the Althea Fund cannot always plan for exposure like this, they do have some procedures in place to try and mitigate potential harm to their organization and supporters. Cristina told me many organizations communicating about abortion have "plans in place for when shit like that does happen." When their Facebook page was flooded with threats, Cristina told me: "I went straight to [our] networks that have lawyers on hand. The national network is known for security resources, so people asked if we wanted to contact them about our physical safety." Althea organizers swiftly reacted to the threats by locking down their social media and turning to their national network for support. Yet these same organizers also had to emotionally process and intellectually prepare for their rapidly changing personal safety.

Abortion stigma and media misinformation perpetuates and normalizes this kind of anti-abortion rage. Knowing this rage exists and is ready to mobilize means Althea organizers, who work daily to protect and provide abortion access, also have personal and organizational safety strategies ready to deploy when they are inevitably threatened. Even though threats faced by Riya, Cristina, and the Althea Fund at-large were persistent and sometimes violent, the organizers navigated it all while still try to manage and harness their supporters' emotions. For example, Althea organizers tried to wield the news organization story and subsequent digital attacks strategically to mobilize their supporter base. The Althea Fund cannot control when attacks will happen, but, as Cristina said, "What we can control is how we respond. So we actually leverage it. We fundraised even more [after the news organization incident]. We raised $15,000 from that." While handling anti-abortion rage is arduous and stressful, Althea organizers have become emotionally nimble enough that they can promptly leverage the most violent of communications to invigorate their supporters. With this, I saw firsthand some of the "stigma resilience" and pride documented by researchers who have previously studied abortion work. A sense of quiet purpose and dogged resilience infiltrated our conversations about these ongoing brushes with stigma and aggression. Though their emotionally charged labor was erratic and at times intense, Althea organizers never once faltered or suggested they were "unsure" about their individual roles in the collective intersectional mission.

DISCUSSION

Althea organizers are doing multifaceted emotional labor as they constantly communicate with various publics. They stay true to their intersectional principles and their callers, but also stand in as the "face" of their organization and for a highly stigmatized issue. This means these organizers take on the brunt of anti-abortion threats while trying to make sure facts and stories about actual abortion experiences are heard.

Stigma and misunderstanding about abortion remain central in U.S. media and society. Though abortion is a safe and common procedure, interpersonal conversations about the subject remain political, divisive, or altogether missing. Statistics and stories about marginalized individuals, "real people," who desire or struggle to access abortion are important to hear and can help humanize and demystify abortion healthcare. Yet, public health policy and media misrepresentation perpetuate silence and shame. This media (mis)representation not only misinforms the public and enables stigma to persist, but it also repeatedly normalizes rage as an acceptable response to abortion. In the face of rampant misinformation, silence, and rage in the public sphere, reproductive justice organizers and activists take it upon themselves to do what it takes to break stigma, correct misinformation, and advocate for robust reproductive rights and healthcare.

Not only do organizers have to vigilantly prepare for anti-abortion rage, though, but they also regularly assuage the emotions of their own choice-oriented supporters. During my year with the Althea Fund, I was reminded daily how an intersectional approach (none of us are free until all of us are free) was understood not as a choice in the work, but as an imperative. Each time a new communication crisis or decision-making moment arose, intersectionality was the main criteria against which messages were measured: Does this reflect our callers' complex lived experiences? Does the narrative we are creating not only accurately depict the intersecting oppressive systems that hinder people from accessing abortion care, but that also thwart their attempts to have and raise children safely? Every meeting and conversation I had at the Althea Fund was evidence these organizers would not purposefully allow each other to take a simpler emotional or communicative road if it meant forgetting the long-term goal: actual reproductive freedom for everyone.

Through their efforts, Althea organizers strategically wielded emotion and new media to form inclusive, intersectional counter-publics built on "solidarity and reciprocity … grounded in a collective experience of marginalization" (Downey and Fenton, 2003, p. 194). Of course, using media for organizing and sharing marginalized stories is nothing new, as "social movements have always engaged in transmedia organizing" using any means available to take their message to the public (Costanza-Chock, 2014, p. 19). However, the intersection of abortion stigma, intersectional consciousness, emotional labor, and new media advocacy is particularly interesting due to the "always on" nature of both the internet and passionately divisive abortion discourse. Any moment in the life of these organizers might become one in need of intellectual, emotional, or technological prowess. Though I am sure people working for liberation have always been relentlessly engaged emotionally in their movements, I wonder how relentless technological engagement changes, enhances, tempers, or intensifies this work.

More recently, through grants and other major donations, Althea has been able to hire more full-time staff and organizers focused solely on advocacy. While this does not mean the threats or labor have lessened, hopefully the digital work, the emotional exposure, and the tangible outcomes can be shared and shouldered by several experienced organizers. Moreover, Althea organizers have also discussed wanting to let callers know they can be part of advocacy work (in the near or distant future) if they feel empowered or called to share their story. However, as always, organizers do not want already vulnerable callers to feel coerced into sharing their stories while they seek funding for healthcare—especially in a neoliberal society where they already feel pressure to prove the value and worth of their humanity.

Moving forward, ideally the Althea Fund and other reproductive justice organizations can continue to expand and make space for people who have had abortions to feel safe and empowered to share that part of themselves. As we move toward a world where abortion is less stigmatized, we move toward a world where a few, brave, visible activists do not carry the emotional burden for all of us. By holding true to their intersectional principles, organizers like those at Althea can also continue to make it apparent to the public that oppression is an intricately layered web, and expansive freedom cannot be obtained when one issue is ignored, silenced, or stigmatized.

DATA AVAILABILITY STATEMENT

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Texas A&M University Institutional Review Board. The ethics committee waived the requirement of written informed consent for participation. Written informed consent was not obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

JG-S designed and performed all research, analysis, writing, and editing of this manuscript.

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Measuring Discriminatory Social Norms Against Children With Disabilities to Improve Communication-Based Programs

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In the Europe and Central Asia region, there are at least five million children diagnosed with some type of disability. These children are likely to be subjected to stigmatization and marginalization, which can lead to discrimination and reduction in access to social services. A pilot study was developed to examine factors affecting the treatment of children with disabilities from a holistic, systematic perspective. Stratified by the social ecological model, 450 respondents participated in a structured interview designed to measure knowledge, attitudes, norms, marginalization, and stigma. The results yielded four conclusions. First, it showed that professionals did not rate differently on the constructs of the conceptual model when compared to nonprofessionals. Second, norms are likely affecting the treatment of children with disabilities. Third, the study shows that there is not enough emphasis on educating and involving community members to improve the treatment and protect the rights of children with disabilities. Finally, the results emphasize the importance of approaching disability from a comprehensive social ecological perspective.

Keywords: disabilities, children, social norms, discrimination, communication, measurement

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INTRODUCTION

Over five million of the children who reside in the Europe and Central Asia region are believed to have some sort of disability, with close to 3.6 million living in residential institutions (UNICEF, 2015). In recent decades, there have been many global initiatives to improve the lives of children with disabilities, such as the *Convention on the Rights of the Child* (CRC) and the *Convention of the Rights of Persons with Disabilities* (CRPD), which outline the responsibilities of the State to protect vulnerable individuals from health, social, economic, cultural, civic, and political discrimination (UN General Assembly, 1989, 2007). Despite such agreements, many children with disabilities face significant challenges and violations of their human rights. Children with disabilities are often deprived of medical access and education and are less likely to have proper nutrition (Byers et al., 2018; UNICEF, 2018). They are also at a higher risk for maltreatment, abuse, and violence (Hibbard and Desch, 2007; Hershkowitz et al., 2010). Girls with disabilities may face two-fold discrimination due to the intersection of their disability and gender (UNICEF, 2013). Further, stigma, prejudice, and ignorance due to the lack of capacity building and trainings related to children with disabilities often get in the way of positive change (UNICEF, 2013).

This study, therefore, seeks to better understand the social-environmental factors that are perpetuating discrimination against children with disabilities in Europe and Central Asia.

Defining Disability

It is important to begin with a common understanding of how disability is defined, as there are several ways in which it can be conceptualized. Perhaps most common, the medical model of disability considers persons with disabilities as having problems that need to be cured (Manago et al., 2017). The medical model implies that abnormality is inherent in disability and encourages the individual to adapt to society. Another model, the charity model, sees persons with disabilities as victims of their impairments in need of sympathy and charity to cope with their (perceived as) tragic situation (Hollenweger and Martinuzzi, 2015). A third, more holistic model, called the social model, began to develop in the 1960's. The social model posits that disability is a limitation in attitudes, institutions, and the environment that prevents full and equal participation of all individuals in society (World Health Organization (WHO) World Bank, 2011). By situating disability within a larger context, the social model allows for a systems level, rather than individualistic, approach to addressing disabilities.

The social model was approved by the WHO and published in the International Classification of Impairments, Disabilities and Handicaps in 1980 (Bickenbach et al., 1999). While progressive at the time, it grew to receive criticism, as the language was ambiguous and still seemed somewhat in line with the medical model [Bickenbach et al., 1999]. Therefore, in 2002, the International Classification of Functioning, Disability, and Health (ICF) described a more inclusive framework that combines the social and medical model, called the biopsychosocial model (World Health Organization (WHO), 2002). The ICF defines disability as "an umbrella term for impairments, activity limitations and participation restrictions" [World Health Organization (WHO), 2002, p. 2]. It is conceptualized by the interaction between health conditions due to diseases, disorders, and injuries and contextual factors. Contextual factors include environmental factors, such as social attitudes, and individual factors, such as education. These constructs influence how a person experiences disability [World Health Organization (WHO), 2002]. Whenever this paper mentions disability, it will employ this human-rights-based definition, drawing upon the biopsychosocial model.

Children With Disabilities in North Macedonia

Accurate data on the number of children living with a disability in North Macedonia is lacking. Estimates from 2010 and 2011 placed the number somewhere between 25,535 and 55,000 children, depending on the formula used [Velichkovski and Chichivalieva, 2010; World Health Organization (WHO) World Bank, 2011]. However, official figures from 2018 reported an estimate of 8,000 children (MLSP, 2018). While this figure includes 700 estimated children unregistered and not in contact with social services, it is still considerably less than external estimates. The discrepancy between official estimates and external estimates indicates that there may be many more unregistered children with disabilities who are being hidden away at home and not receiving any official services.

Even children who are registered may not receive the support to which they are entitled. Despite ratifying the CRPD in 2011 and accepting by succession the CRC in 1993, national policies are often poorly implemented (United Nations, 2020). North Macedonia's federal provisions for children with disabilities are mainly handled by the health, education, and social sectors, but a 2015 assessment of the capacity of these sectors found that there was little integration between them and no shared vision to comprehensively meet the needs of children with disabilities (Hollenweger, 2015). Further, the current public funding schemes seem to promote exclusion of children with disabilities by privileging specialized institutions over inclusion (Hollenweger, 2015).

Many organizations beyond the federal government provide support for children with disabilities and their families; a mapping in 2014 identified 136 associations, foundations, and informal civic initiatives involved in the field of inclusion of and support for children with disabilities (Open the Windows, 2014). However, these organizations are not evenly distributed, and the capital city is the only place in which persons with all types of disabilities are supported (Open the Windows, 2014). Similar to the federal sectors, there is little communication or cooperation among non-governmental organizations or with the public sector.

The effectiveness of the systems and organizations is likely further affected by the knowledge, attitudes, and practices (KAP) of those working in them. While there is little information on the specific perspectives of professionals in North Macedonia about children with disabilities, it may be possible to generalize the KAP of professionals from the views of the general population. A 2014 KAP study in North Macedonia found that 69% of the population views disability through either the medical or the charity model and that over half of participants reported having no or low awareness of children with disabilities (UNICEF, 2014). Additionally, only 4% of the population was in support of inclusive education, with 48% saying children with disabilities should be in separate schools (UNICEF, 2014). The level of rejection for children with disabilities also seems to vary depending on the nature of the relationship being explored. For example, depending on the type of disability, between 63 and 79% of respondents found it acceptable for a child with a disability to live in the same settlement or street with their own child; comparatively, only 2–6% found it acceptable for a child with a disability to marry their child (as adults) (UNICEF, 2014).

Conceptualizing Discrimination

The CRPD describes discrimination as "any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field" (UN General Assembly, 2007, Article 2). However, knowing the definition of discrimination is not sufficient for eliminating it. To reduce discrimination against children with disabilities, it is imperative to determine the factors that lead to such behaviors. The conceptual model in **Figure 1** is based on a systematic review of behavior change theories, disability, and discrimination conducted by the authors in 2017 (Sood et al., 2020).

The first constructs of the model are knowledge and attitudes, as they are precursors to behavior; they are the important steps that lead to the intention to practice (or to not practice) a behavior (Ajzen, 1991). The connection between knowledge, attitudes, and behavior has been extensively studied and is generally accepted. However, knowledge and attitudes alone are not always sufficient to predict behavior; social norms may also be a key component. Social norms are the behaviors that a group of people believe to be typical or appropriate. They are the unwritten rules that guide behavior (Bicchieri et al., 2018). Social norms do not always align with personal attitudes. Someone may approve of a behavior but choose not to practice it because of their beliefs about the approval and behavior of others. Social norms are generally divided into two components; although the terminology differs throughout the literature, this paper will refer to descriptive and injunctive norms. Descriptive norms are beliefs about what other people are doing, while injunctive norms are beliefs about what other people think people should do (Mackie et al., 2015). It is important to measure both descriptive and injunctive norms to understand normative influences on a behavior.

Taken together, knowledge, attitudes, and social norms can start to affect stigma. Stigma was considered integral to the model because discrimination is often conceptualized as the behavioral reaction to the negative prejudices of stigma (Link and Phelan, 2001; Corrigan and Watson, 2002; Major and O'Brien, 2005; Van Brakel, 2007; Van Brakel et al., 2012). The World Health Organization defines stigma as "a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society" [World Health Organization (WHO), 2001, p. 17]. Stigma has been conceived as a compound of multiple components: labeling, stereotyping, separation, and status loss and discrimination (Link and Phelan, 2001). Stigma includes recognizing socially salient differences, assigning negative attributes to those differences, and creating a sense of "otherness" by reacting to those differences (Green et al., 2005). This study also considers perceived stigma (beliefs about the amount of stigmatization perpetrated by others) and perceived marginalization (beliefs about the amount of marginalization perpetrated by others), as these can affect stigmatization from a normative approach.

Stigma ultimately leads to discrimination through avoidance, withholding help, segregation, and coercive treatment (Van Brakel, 2007; Social Exclusion Knowledge Network, 2008). Stigma can reduce access to treatment and services, as well as increase social exclusion (US DHHS, 1999; Green et al., 2005; Stuber et al., 2008). Unequal power dynamics caused by these practices continue the cycle of exclusion, which can result in health inequities (Krieger, 2000; Social Exclusion Knowledge Network, 2008). In this case, we are looking at experiences of marginalization on the basis of a person's disability.

In the conceptual model, communication interventions and activities are placed at the beginning, to emphasize their important role in reducing discrimination against children with disabilities. Communication that takes an evidence- and rights-based approach and emphasizes participation from all stakeholders can be used in behavior and social change interventions. These approaches are especially effective when they empower communities to take an active role in the decisions that affect their lives (UNICEF, 2019).

Therefore, the conceptual model shows that communication approaches and activities can promote positive changes in attitudes and knowledge about children with disabilities, which can affect social norms, perceived marginalization, and perceived stigma. These can lead to a reduction in stigma, which contributes to decreasing discrimination against children with disabilities. Sociodemographic variables, like age, sex, and education, are placed across the entire model, as they can also affect how people think and how they behave.

Measuring Discrimination

In order to assess discrimination against children with disabilities, and to be able to track changes in the amount of discrimination they face, it is necessary to have valid and reliable tools for measurement. However, current research on the conceptualization and practice around children with disabilities vary in quality. A systematic review by the authors of 44 studies on discriminatory attitudes and social norms related to children with disabilities revealed that such research generally lacks tools to accurately measure attitudes or social norms, clear definitions of key concepts, involvement of children, mixed-methods approaches, participatory methods, and a focus on social norms (Sood et al., 2020). Furthermore, the review found that most studies and programs do not approach research on discrimination against children with disabilities holistically or systematically. Of the 44 articles, only 25 used a theoretical framework, and only five of those used the Social Ecological Model (SEM) (Sood et al., 2020). The SEM stresses the importance of the multifaceted interactions between social and environmental factors and how they impact behavior (UNICEF, 2016). Given the understanding of disability through the biopsychosocial model, it is especially important to take such a multilevel approach to disability research. Research using the SEM as its guiding framework would seek to gain the perspectives from stakeholders at every level: individual, family, community, and policy/systems. While children with disabilities, children without disabilities, parents, and professionals were all represented in the different peer-reviewed studies, only two of the 44 examined more than one type of audience (Sood et al., 2020). Additionally, the studies focused predominantly on knowledge, attitudes, and practice, with social norms being noticeably absent. If norms perpetuate discrimination at the social level, then they must be clearly defined, and tools must exist to measure the normative constructs.

Other systematic reviews on attitudes, beliefs, and prejudice against people with disabilities found similar gaps. For example, a systematic review of 20 studies on the relationship between students' attitudes and the social participation of peers with

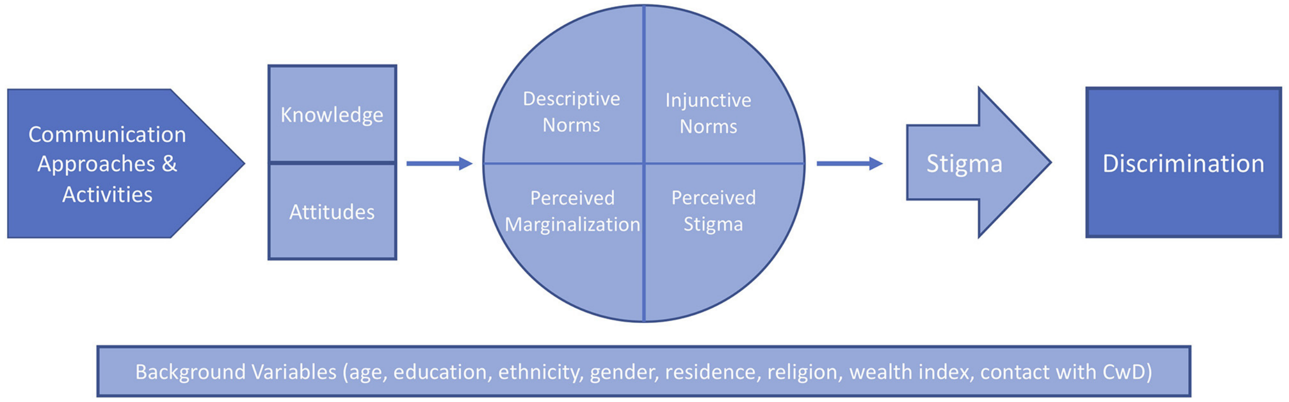

FIGURE 1 | Conceptual model connecting communication approaches and activities to discrimination.

disabilities found that studies were using inconsistent measures of attitudes (De Boer et al., 2012). Furthermore, of the 20 studies, only three presented empirical data on the connection between attitudes and discrimination and social exclusion of children with disabilities (De Boer et al., 2012). Through a systematic review of nurses' attitudes toward children with disabilities, Cervasio (2010) concluded that "scant" research exists on the connection between health professionals' attitudes and the treatment children with disabilities receive. Scior (2011) reviewed 75 articles on public awareness, attitudes, and beliefs about intellectual disability and found mainly descriptive accounts of attitudes and a lack of high-quality evaluations. The author concluded that "there is a need for research that considers the complex processes involved in the formation of stigma, prejudices and discrimination that can negatively affect the opportunities available to people with intellectual disabilities and their social inclusion" (Scior, 2011, p. 2179).

The Present Study

The current study attempts to address the aforementioned gaps in research by creating a set of validated measures for the constructs of the conceptual model. It investigates the relationships between social-environmental factors and discrimination by measuring key stakeholders' knowledge, attitudes, social norms, and stigma toward children with disabilities and their families. The study aims to determine the importance of a holistic and systematic approach for realizing the rights of children with disabilities.

MATERIALS AND METHODS

Materials

A quantitative questionnaire was developed by adapting pre-existing measures and creating new ones where necessary. The questionnaire was designed to capture knowledge, attitudes, normative beliefs, perceived marginalization, perceived stigma, and personal stigmatization of children with disabilities. As this was a pilot study, more questions were included than typical, so as to assess the best way to measure the constructs of the conceptual model. The draft tools were then reviewed by multiple experts in disability and researchers with experience in interviewing children. After revisions, the tools were translated into Macedonian and pretested in the field with the help of a local research agency to ensure comprehension and cultural appropriateness. Pretesting the tools for all children, specifically children with disabilities, was given greater emphasis to ensure that the instructions for the activities and the questions were simple to understand. The tool was finalized for pilot testing based on the results of the pretest.

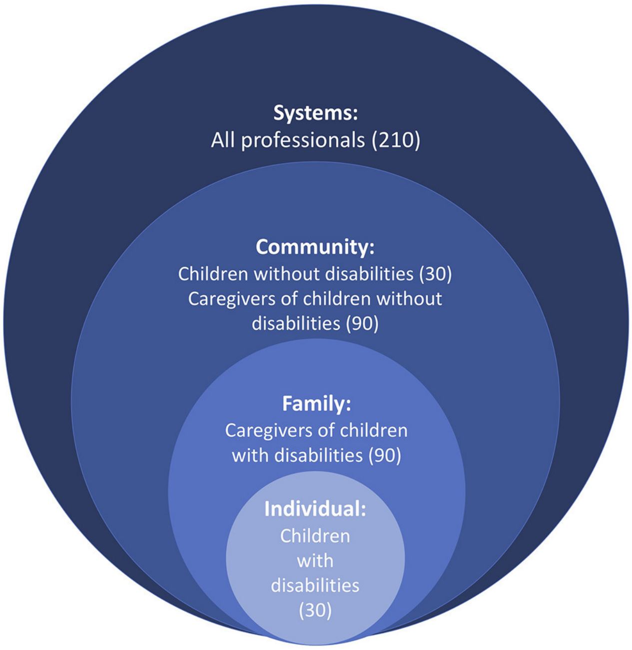

FIGURE 2 | Respondent groups distributed by the social ecological model.

Study Sample

Fifteen different stakeholder groups spanning the SEM were identified as important to the treatment of children with disabilities in North Macedonia (**Figure 2**). These included children with disabilities (ages 12–18 years) at the individual level; caregivers of children with disabilities (three groups corresponding to the child's age: 0–3, 3–6, and 6–11 years) at the family level; children without disabilities (ages 12–18 years) and caregivers of children without disabilities (three groups corresponding to the child's age: 0–3, 3–6, and 6–11 years) at the community level; and academic professionals (both teachers and administrators), health professionals (for both maternity and school-aged children), social workers, civil society professionals and government officials at the policy level.

When identifying participants, the CRPD definition of disability was used: a "long-term physical, mental, intellectual, or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD, Article 1, 2006). The study aimed to look at discrimination against children with disabilities as a whole, therefore no specific disability was sampled for.

The three age groups for children were identified in conjunction with local experts as representing three critical phases in children with disabilities' lives: their first interaction with the healthcare system and the period during which institutionalization is most likely, their first interaction with the education system, and their expanding connection with, and understanding of and by, peers. While it is understood that the experiences of children with disabilities vary across their lifetime, the scope of the study limited the number of age groups that could be assessed. The age groups not assessed in this study offer opportunities for further study.

Pretesting of the tools was unsuccessful with children with disabilities under the age of 12. Based on the recommendation made by local disability experts, children with disabilities ages 12–18 were interviewed instead, while still interviewing parents that corresponded to the three age groups of interest. These decisions were then mirrored for children without disabilities and caregivers of children without disabilities for comparability of data.

The convention of using 30 individuals per group is common for pilot studies and thus was used in the present study (Johanson and Brooks, 2010). A list of children with disabilities and their parents was collected from government records and consultations with health and social service NGO's who work with children with disabilities and their parents. The government and non-governmental health and social workers assisted with sample selection by informing individuals of the study and providing them with a phone number to call, if they wished to participate. The children without disabilities and their parents were purposively selected, to the extent possible, from the same residential location or school as their counterparts. The professional sample was purposively selected from a list of Disability Persons Organizations, to cover different professional ranks and job responsibilities.

For the purposes of analysis of this study, the fifteen stakeholder groups were condensed into four aggregate groups corresponding to each SEM level. At the individual level were children with disabilities themselves (30 individuals). The three groups of caregivers of children with disabilities were categorized together as the family level (90 individuals). Both children without disabilities and their caregivers were considered community members (120 individuals). Finally, all professionals were combined to represent the policy/systems level (210 individuals).

TABLE 1 | Factor analysis results for scale creation.

Variable	Eigenvalue	Cronbach's alpha
Attitudes	2.0406	0.780
Perceived marginalization	4.78309	0.894
Perceived stigma	1.55117	0.795
Stigma	1.17632	0.704

Variables

The quantitative questionnaire asked questions to measure the variables of interest, as identified in the conceptual model: knowledge, attitudes, normative beliefs, perceived marginalization, perceived stigma, and personal stigmatization of children with disabilities. As this was a pilot study, it was first necessary to analyze the questions themselves. This was done by looking at the percentage of "don't know" or "refused to respond" answers to each question, along with qualitative input from data collectors and statistical tests, such as factor analyses and Cronbach's alpha. Factor analysis was performed on the scales for attitudes, perceived marginalization, perceived public stigma, and personal stigmatization of children with disabilities. **Table 1** lists the eigenvalues and Cronbach's α associated with these factor analyses.

Sixteen knowledge questions were asked to all respondents, conceptualized as the ability to identify types of disabilities and impairments, with response options of no, maybe, or yes. For knowledge, four questions with high proportions of refused to respond and don't know were removed and the remaining 12 were evenly split into knowledge of intellectual disabilities and knowledge of physical disabilities.

All respondents were then asked attitudinal questions, in which they rated their agreement with a series of 15 statements, e.g., "children with disabilities can do lots of things for themselves," using a five-point Likert scale from strongly disagree to strongly agree. After statistical analysis, the final scale for attitudes included five items from the original 12 ($\alpha = 0.78$).

Normative questions were based on vignettes. The vignettes described a child with a disability and combinations of age group (0–3, 3–6, 6–11), type of impairment (physical or intellectual), and key behavior of interest (deinstitutionalization, inclusive education, or general human rights). After being read the vignette, respondents were asked questions to assess descriptive and injunctive norms. First, they were asked what they would do, e.g., "Where is the best place for this child to live? At home, with a foster family, or at an institution?" This was followed by asking what they thought their family, community, and society would approve of, e.g., "Would your family members approve of keeping the child at home, placing her in a foster family, or putting her in an institution?" Next, they were asked to rate the extent to which [from not at all (1) to completely (5)]

TABLE 2 | Demographics overall and by social ecological model level.

	Total	Individual	Family	Community	Society	χ^2 *P*-value
N	450	30 (6.7%)	90 (20.0%)	120 (26.7%)	210 (46.7%)	
Age						
Mean (sd)	37.2 (12.7)	16.6 (1.9)	37.1 (5.7)	30.0 (10.7)	44.4 (11.3)	
Gender***						
Male	112 (24.9%)	17 (56.7%)	22 (24.4%)	38 (31.7%)	35 (16.7%)	0.000
Female	338 (75.1%)	13 (43.3%)	68 (75.6%)	82 (68.3%)	175 (83.3%)	
Education***						
Primary	34 (7.6%)	6 (20%)	6 (6.7%)	22 (18.3%)	0 (0.0%)	0.000
Secondary	160 (35.6%)	24 (80.0%)	45 (50.0%)	55 (45.8%)	36 (17.1%)	
College+	256 (56.9%)	0 (0.0%)	39 (43.3%)	43 (35.8%)	174 (82.9%)	
Income***						
Low	47 (10.4%)	0 (0.0%)	24 (26.7%)	14 (11.7%)	9 (4.3%)	0.000
Medium	174 (38.7%)	2 (6.7%)	38 (42.2%)	48 (40.0%)	86 (41.0%)	
High	121 (26.9%)	0 (0.0%)	17 (18.9%)	32 (26.7%)	72 (34.3%)	
Missing	108 (24.0%)	28 (93.3%)	11 (12.2%)	26 (21.7%)	43 (20.5%)	

****p-value <0.001.*

their decision from the first question would be affected by what their family/community/society expects them to do. Each adult respondent was asked the series of questions about two vignettes, one about a physical impairment and one about an intellectual impairment.

Twelve questions were asked to all respondents to assess perceived marginalization. Participants stated how often they thought the event happened to children with disabilities or their families, from never (1) to multiple times per day (6). The questions included events such as "they receive poorer service than other people in restaurants or stores." The final scale for marginalization included nine items from the original 12 ($\alpha = 0.89$).

Because of the likelihood that people would not admit to directly committing discriminating actions against children with disabilities, due to social desirability bias, this study looked at personal stigmatization of children with disabilities as the outcome measure. Personal stigmatization was operationalized as a set of eight questions designed to capture the components of labeling, stereotyping, and separation when taken together, with answers ranging from strongly disagree (1) to strongly agree (1). To capture perceived stigma, all respondents were asked to rate other's agreement with those same eight questions. The final scales for perceived stigma and personal stigmatization both included three items from the original eight ($\alpha = 0.795$ and $\alpha = 0.704$, respectively).

Ethical Considerations

The study received ethical approval from Drexel University, as well as independent approval from Health Media Lab. All adult participants gave informed consent before the start of the study. Child participants gave assent to participate, with their parent or guardian also consenting for their participation. Children were interviewed using specially trained local social workers that have experience in working with and researching children with and without disabilities.

Data Analysis

Statistical analysis was performed on STATA 15 with results from completed structured interviews. Questionnaires were considered complete if at least 80% of the questions were answered.

To create the indicators, all Likert scales were recoded to start at 0 instead of 1 and any dichotomous questions were recoded as 0/1. All questions that were worded in an opposite way of the rest of the scale were reverse coded. Responses that included "don't know" and "refused to answer" were recoded as missing data. The final indicators for attitudes, perceived marginalization, perceived stigma, and personal stigmatization were created by adding across the final scale items. Because the distribution of these additive variables proved to be skewed, dichotomous variables were created for each. Respondent scores were coded as low or high (for knowledge, marginalization, and stigma) or as negative or positive (for attitudes).

Descriptive analyses were completed for demographic information, with significance testing (*t*-test for means, chi-squared for all others) to see if the sample varied by the background characteristics. Frequencies and percentages were calculated for all construct indicators. Then, chi-squared tests were conducted to look for significant differences in any of the construct indicators by SEM level. Subsequently, bivariate analysis was done through logistical regression, followed by a multiple logistic regression that included all variables in the model.

RESULTS

Description of the Sample

The sample contained statistically significantly more females (75.1%) than males (24.9%) ($p = 0.000$). For children with disabilities, the mean age was 16.6 years ($sd = 1.9$); for caregivers of children with disabilities, it was 37.1 years ($sd = 5.7$); for the community level, 30.0 years ($sd = 10.7$), and for professionals, 44.4 years (*sd* = 11.3). Most (56.9%) of the participants were at least college-educated, whereas 35.6% had only completed secondary school and 7.6% had only completed primary school. **Table 2** summarizes sociodemographic characteristics for the entire sample, by SEM level.

Frequency Results

More (58.4%) of the sample had high knowledge of physical disabilities as compared to low levels (41.6%). On the other hand, slightly less than half (48.0%) of the sample had high knowledge of intellectual disabilities. The respondents mainly had positive attitudes toward children with disabilities (76.9% compared to 23.1% negative), yet most (58.4%) respondents perceived high amounts of public stigma and high amounts of marginalization (78.0%). When considering norms, perceptions of approval of the desired behavior decreased with social distance from the respondent. Of adult participants, 35.6% of participants said they themselves approved of the desired behavior, while 32.8% thought that their family approves of the desired behavior, 25.9% thought their community does, and only 17.4% thought society does. Similarly, the effect of others' expectations on the behavior of the adult respondents decreased with social distance from the individual. Sixty nine percent of respondents are affected by their family's expectations, while only 62.3 and 51.3% said they are affected by their community and society's expectations, respectively. Ultimately 58.4% ($n = 263$) reported high levels of personal stigmatization of children with disabilities. **Table 3** presents the frequency results overall and by SEM level (see next section).

Comparison by SEM

When the variables for each construct were analyzed by SEM level—individual, family, community, and society—many were not statistically significant. However, attitudes, family expectations, perceived stigma, perceived marginalization, and personal stigmatization all had statistically significant differences by SEM level.

Although not statistically significant, it is interesting to note that only 58.1% of professionals had high levels of knowledge of physical disabilities, which was less than both children with disabilities (70.0%) and their caregivers (63.3%). Similarly, fewer professionals had high levels of knowledge of intellectual disabilities than did caregivers of children with disabilities (50.5 vs. 55.7%, respectively).

There were statistically significant differences in proportions of SEM level with positive attitudes ($p = 0.009$). Community members had the lowest proportion of positive attitudes toward children with disabilities (65.8%), while caregivers of children with disabilities had the highest (83.3%). Eighty percent of professionals had positive attitudes, the same proportion as children with disabilities themselves.

Rates for approval of the desired behavior in the norms questions were similar across SEM levels for self, family, community, and society approval variables. Caregivers of children without disabilities had the lowest rates of approval of the desired behaviors for three of the approval variables: 28.9% for self-approval, 24.4% for family approval, and 18.9% for community. For belief that society approves of the desired behavior, caregivers of children with disabilities had the lowest proportion (14.4%).

Professionals (62.9%) were less affected by their family's expectations than caregivers of children with disabilities (76.7%) and caregivers of children without disabilities (75.6%) ($p = 0.018$). However, there were no statistically significant differences in the proportions affected by community and society expectations.

Community members (86.7%) and professionals (83.3%) perceived more marginalization than children with disabilities (66.7%) and their caregivers (57.8%) did ($p = 0.000$). There were also statistically significant differences in perceived stigma by SEM ($p = 0.000$). Only 26.7% of children with disabilities perceived high stigma, compared to 76.7% of caregivers of children with disabilities. About 70% of both community members and professionals perceived high levels of stigmatization of children with disabilities.

Bivariate Results

There were no statistically significant differences in personal stigmatization of children with disabilities by education, gender, or age. The odds of stigmatization increased with increasing income. Also compared to other respondents, children with disabilities were significantly less likely to display stigma toward other children with disabilities ($OR = 0.45$, $p = 0.38$). On the other hand, community members were at 1.61 times the odds of highly stigmatizing children with disabilities, as compared to all other respondents ($p = 0.034$).

When looking at the key constructs, knowledge of physical disabilities, attitudes, being affected by society's expectations, and perceived stigma were all significantly related to levels of personal stigmatization of children with disabilities. Counter to expectations, those with high levels of knowledge of physical disabilities were at higher odds of personally stigmatizing children with disabilities ($OR = 1.78$, $p = 0.003$). However, having positive attitudes toward children with disabilities was protective against highly stigmatizing children with disabilities ($OR = 0.36$, $p = 0.000$). Additionally, those who reported being highly affected by society's expectations were at almost twice the odds of highly stigmatizing children with disabilities ($OR = 1.95$, $p = 0.001$). Finally, those with high levels of perceived public stigmatization of children with disabilities were 7.49 times more likely of themselves highly stigmatizing children with disabilities ($p = 0.000$). **Table 4** details the bivariate logistic regression results.

Multivariate Results

Similar to the bivariate logistic regressions, the multivariate logistic regression showed significant differences in personal stigmatization of children with disabilities by correct knowledge of physical disabilities, attitudes, being affected by society's expectations, and perceived stigmatization of children with disabilities. When adjusting for all the variables in the model

TABLE 3 | Frequency results for all constructs in the conceptual model, by total and by social ecological model level.

	Total	Individual	Family	Community	Society	χ^2 *P*-value
N	450	30 (6.7%)	90 (20.0%)	120 (26.7%)	210 (46.7%)	
Knowledge of physical disabilities						
Low	187 (41.6%)	9 (30.0%)	33 (36.7%)	57 (47.5%)	88 (41.9%)	0.232
High	263 (58.4%)	21 (70.0%)	57 (63.3%)	63 (52.5%)	122 (58.1%)	
Knowledge of intellectual disabilities						
Low	234 (52.0%)	19 (63.3%)	40 (44.4%)	71 (59.2%)	104 (49.5%)	0.086
High	216 (48.0)	11 (36.7%)	50 (55.7%)	49 (40.8%)	106 (50.5%)	
Attitudes**						
Negative	104 (23.1%)	6 (20.0%)	15 (16.7%)	41 (34.2%)	42 (20.0%)	0.009
Positive	346 (76.9%)	24 (80.0%)	75 (83.3%)	79 (65.8%)	168 (80.0%)	
Personal approval of desired behavior						
Undesired	251 (64.4%)		56 (62.2%)	64 (71.1%)	131 (62.4%)	0.313
Desired	139 (35.6%)		34 (37.8%)	26 (28.9%)	79 (37.6%)	
Family approval of desired behavior						
Undesired	262 (67.1%)		53 (58.9%)	68 (75.6%)	141 (67.1%)	0.059
Desired	128 (32.8%)		37 (41.1%)	22 (24.4%)	69 (32.9%)	
Community approval of desired behavior						
Undesired	289 (74.1%)		62 (68.9%)	73 (81.1%)	154 (73.3%)	0.162
Desired	101 (25.9%)		28 (31.1%)	17 (18.9%)	56 (26.7%)	
Society approval of desired behavior						
Undesired	322 (82.6%)		77 (85.5%)	75 (83.3%)	170 (81.0%)	0.614
Desired	68 (17.4%)		13 (14.4%)	15 (16.7%)	40 (19.1%)	
Family expectations*						
Unaffected	121 (31.0%)		21 (23.3%)	22 (24.4%)	78 (37.1%)	0.018
Affected	269 (69.0%)		69 (76.7%)	68 (75.6%)	132 (62.9%)	
Community expectations						
Unaffected	125 (37.7%)		34 (37.8%)	28 (31.1%)	85 (40.5%)	0.308
Affected	243 (62.3%)		56 (62.2%)	62 (68.9%)	125 (59.5%)	
Society expectations						
Unaffected	190 (28.7%)		49 (54.4%)	41 (45.6%)	100 (47.6%)	0.440
Affected	200 (51.3%)		41 (45.6%)	49 (54.4%)	110 (52.4%)	
Personal opinion of stigma*						
Low	187 (41.6%)	18 (60.0%)	41 (45.6%)	40 (33.3%)	88 (41.9%)	0.043
High	263 (58.4%)	12 (40.0%)	49 (54.4%)	80 (66.7%)	122 (58.1%)	
Perceived marginalization***						
Low	99 (22.0%)	10 (33.3%)	38 (42.2%)	16 (13.3%)	35 (16.7%)	0.000
High	351 (78.0%)	20 (66.7%)	52 (57.8%)	104 (86.7%)	175 (83.3%)	
Perceived stigma***						
Low	140 (31.1%)	22 (73.3%)	21 (23.3%)	36 (30.0%)	61 (29.1%)	0.000
High	310 (68.9%)	8 (26.7%)	69 (76.7%)	84 (70.0%)	149 (70.9%)	

**p-value <0.05,* ***p-value <0.01,* ****p-value <0.001.*

(age, gender, socioeconomic status, education, knowledge of physical disabilities, knowledge of intellectual disabilities, attitudes, descriptive norms, injunctive norms, perceived marginalization, and perceived stigma), those with high levels of knowledge of physical disabilities were at twice the adjusted odds of high levels of personal stigmatization of children with disabilities ($AOR = 2.04$, $p = 0.011$). Being affected by society's expectations and perceiving high levels of stigmatization of children with disabilities also led to increased adjusted odds of highly stigmatizing children with disabilities ($AOR = 2.61$, $p = 0.004$; $AOR = 9.83$, $p = 0.000$, respectively). On the other hand, those with positive attitudes had significantly lower adjusted odds of highly stigmatizing children with disabilities ($AOR = 0.33$, $p = 0.002$). The multivariate logistic regression results are shared in **Table 5**.

TABLE 4 | Bivariate logistic regression results with stigma as the dependent variable.

	OR	*P*-value
Age	1.01	0.521
Gender		
Female	1.37	0.154
Education		
Secondary	0.97	0.925
College+	1.23	0.572
Income		
Medium*	0.5	0.049
High	0.74	0.422
Missing	0.51	0.072
SEM level		
Individual*	0.45	0.038
Family	0.82	0.390
Community*	1.61	0.034
Systems	9.73	0.888
Knowledge of physical disabilities*	1.78	0.003
Knowledge of intellectual disabilities	1.38	0.094
Attitudes***	0.36	0.000
Personal approval of desired behavior	0.76	0.193
Family approval of desired behavior	0.7	0.101
Community approval of desired behavior	0.75	0.209
Society approval of desired behavior	1.11	0.708
Family expectations	1.36	0.161
Community expectations	1.3	0.215
Society expectations***	1.95	0.001
Perceived marginalization	1.51	0.070
Perceived stigma***	7.49	0.000

**p-value <0.05, ***p-value <0.001.*

TABLE 5 | Multivariate logistic regression results with stigma as the dependent variable.

Independent variables	Adjusted odds ratio	$P > z$
Age	1	0.719
Gender	1.33	0.358
Education		
Secondary	0.45	0.452
College+	0.6	0.639
Income		
Medium	0.46	0.094
High	0.44	0.104
Missing	0.59	0.319
SEM level		
Family	0.78	0.497
Community	1.99	0.066
Knowledge of physical disabilities*	2.04	0.011
Knowledge of intellectual disabilities	0.88	0.653
Attitudes**	0.33	0.002
Personal approval of desired behavior	1.1	0.804
Family approval of desired behavior	1.09	0.862
Community approval of desired behavior	0.61	0.333
Society approval of desired behavior	1.34	0.468
Family expectations	1.04	0.932
Community expectations	0.58	0.249
Society expectations**	2.61	0.004
Perceived marginalization	1.37	0.343
Perceived stigma***	9.83	0.000

**p-value <0.05, **p-value <0.01, ***p-value <0.001.*

DISCUSSION

Four main conclusions can be drawn from the results of this study, all related to conceptualizing and addressing the treatment of children with disabilities from a systematic perspective. These include the comparison of professionals to nonprofessionals, the role of social norms in discrimination against children with disabilities, the ratings of community members across variables in the model, and the importance of addressing discrimination through multilevel approaches.

The first inference is that professionals concerned with children with disabilities, those highly educated and trained to work on issues to improve the treatment and protect the rights of children with disabilities, did not rate differently on the constructs of the model when compared to nonprofessionals. The professionals included in this study included health workers, teachers, school administrators, social workers, employees of civil society organizations, and government officials. One would anticipate, or at least hope, that more of these professionals would have high levels of knowledge of both physical and intellectual disabilities, that more would have positive attitudes, and that fewer would be affected by others' expectations when it comes to doing the "right" thing for children with disabilities. However, there were no notable differences in these variables when comparing the professionals to respondents in other levels of the SEM. In fact, though not statistically significant, fewer professionals had high levels of knowledge of physical disabilities than did children with disabilities and their caregivers; similarly, fewer professionals had high levels of knowledge of intellectual disabilities than did caregivers of children with disabilities. The undesired results for professionals are underscored by looking at the outcome variable: almost 60% of the professionals fell into the high personal stigmatization of children with disabilities category.

This finding, supported by the preexisting research that showed a lack of capacity of the professionals involved in supporting children with disabilities in North Macedonia, indicates a need for social and behavior change interventions targeting the systems level (Hollenweger, 2015). Training on technical aspects alone is not sufficient, though; if discrimination against children with disabilities is to be reduced, any interventions for professionals will need to be accompanied with communication messages that encourage destigmatizing. At the policy level, advocacy approaches, such as coalition-building, community mobilization, and communication of evidence-based justifications for programs, are often effective (Servaes and

Malikhao, 2017). Advocacy approaches can offer an opportunity for the voices of children with disabilities themselves to be heard by centering their stories and experiences; such participation is a vital component of human-rights-based advocacy approaches (Callus and Camilleri Zahra, 2017). Social mobilization focused on uniting partners at the national and community levels for a common purpose would be especially beneficial, given that professionals in North Macedonia are often described as not collaborating (Hollenweger, 2015). However, since not all of the professionals work directly with policy, advocacy approaches should be combined with more targeted messaging to the individual professions, along with communication interventions for the general public. For example, teachers and administrators should be targeted with communication messages on inclusive education, while social and health workers involved in disability identification and registration could be targeted with messages about de-institutionalization.

Secondly, the results demonstrate that social norms associated with expectations of others are likely affecting the treatment of children with disabilities. Social scientists have wrestled with the concept of social norms for quite some time, specifically what they are, how they shape behavior, and how individuals and groups are influenced by norms. While sociologists tend to emphasize the role of norms in defining society and in dictating social behaviors, social psychologists have focused more on why individuals follow social norms (Marcus and Harper, 2015). It is not surprising that there is great diversity in how social norms have been conceptualized and continue to be understood.

Broadly speaking, social norms are the unwritten rules that guide human behavior; they are in other words, what we do, what we believe others do, and what we believe others think we should do [World Health Organization (WHO), 2010]. Social norms inherently require a reference group, i.e., a network of people to whom we identify and compare ourselves (Lapinski and Rimal, 2005). This reference group determines norms because identity with a specific group influences whether or not a behavior is considered normative within the group and, in turn, may predict whether or not a new behavior will be adopted (Goldstein et al., 2008).

Insofar as social norms are considered an inherent characteristic of individuals embedded within a larger social system, norms are rules or expectations held by social groups that guide behaviors (Mackie et al., 2015). Members of a group expect and are expected to follow and are motivated to follow norms because of expectations of sanctions for non-adherence and rewards for adherence. Two conditions have to be satisfied for a social norm to exist. First, individuals have to be aware of the norm and that it applies to them, and second, individuals conform to the norm if both of the following conditions are satisfied: they expect a majority of their social network to conform to the norm and they believe that a sufficiently large part of their social network think that they ought to conform to the norm and may sanction them if they do not. It is these expectations that keep people from "cheating" out of concern about what others will think of them and may do to them. In this definition of social norms, reciprocal expectations (norm of reciprocity) in which rewards and benefits received should also be returned, establishes an interdependence impacting the behavior of individuals within a social system.

One example of the existence of social norms within the study results is illustrated by examining the responses of community members for the descriptive and injunctive norms variables. Overall, fewer community members believed that their social networks approved of the desired behavior and more community members expressed being affected by their social networks. Coupled with the fact that community members were least likely to choose the desired behavior themselves, it is likely that discriminatory social norms are at least somewhat dictating how community members view and subsequently treat children with disabilities. In other words, the community members, specifically caregivers of children without disabilities, believe other people don't make the desired choice and believe that other people expect them to not make the desired choice, and subsequently are more likely to not make the desired choice.

Communication approaches in this context can address discriminatory norms toward children with disabilities by working at the community level to promote participatory deliberation on social justice for children with disabilities, the end result being that deliberations about the treatment of children with disabilities can lead to collective decisions and public commitments to improve systemic stigma. The underlying philosophy is that people need to see each other committing to change in order for change to occur.

The argument for normative influence in the treatment of children with disabilities is also supported by the trend of decreasing proportions of perceived approval of the desired behavior as the social distance from the individual increases (self > family > community > society). What this demonstrates is that people have their own opinions and are likely to be familiar with the opinions of those close to them. However, as one broadens the field and examines perceptions of people and institutions at the outer systems and policy levels of the SEM, individuals are less likely to know the "truth" and more likely to make assumptions about what these distant others think, feel, and do. In the absence of interpersonal communication, these false assumptions sustain themselves, making norms essentially a communication phenomenon (Berkowitz, 2004; Yanovitzky and Rimal, 2006). Therefore, one way to overcome this is through communicating to individuals that their beliefs are congruent with the larger majority. If norms are indeed a factor affecting levels of stigma, then communication activities are an essential component of programming to improve the treatment of children with disabilities.

The results also suggest that not enough emphasis has been placed on educating and involving community members to improve the treatment and protect the rights of children with disabilities. The respondents in this SEM level, both children without disabilities and their caregivers, had the lowest proportions of high levels of knowledge of physical and of intellectual disabilities, positive attitudes, and approval of the "desired" behavior in the norm's vignettes, as compared to all other SEM levels. While such results are to be expected—as, according to Intergroup Contact Theory, those without regular direct contact with children with disabilities are less likely to have positive attitudes and beliefs—they are not preferred (Pettigrew, 1998). Improving general community awareness and beliefs is especially important since community members as a whole are an integral part of the creation of the norms that continue to violate the human rights of children with disabilities.

Communication approaches have been successfully used by many organizations to raise communities' awareness and affect communities' attitudes (Johnson et al., 2005; Limani et al., 2018). Social change communications strategies at this level would need to emphasize dialogue and interpersonal communication. Some methods include the use of theater, animation, media, partnering with organizations to create education workshops, and empowering youth (UNICEF, 2016).

Finally, the results emphasize the importance of approaching disability from a comprehensive perspective. Even with the small sample size, there were statistically significant differences in level of personal stigmatization of children with disabilities in one indicator of every construct: knowledge of physical disabilities, attitudes, injunctive norms, and perceived stigma. If all constructs affect stigma, and thus affect discrimination and the violation of the basic rights of children with disabilities, then all are important when designing programs and interventions. This is especially important if norms are conceptualized as part of a larger equation of behavior and social change. In this theorizing, norms are considered to be an intermediate step that have to change in order to accomplish positive outcomes. The use of a broader social-ecological perspective in this type of theorizing situates individuals within their broader environment (inter-personal, community, institutional, societal etc.) and allows for analysis at different levels of influence and the development of strategies to impact them. A human rights-based approach to communication programming, is therefore grounded within larger social, political and cultural systems. Equally, it is important to monitor and evaluate all constructs in order to track the improvement in the realization of the fundamental rights of children with disabilities.

Limitations

As with every study, this study was not without limitations. Perhaps most significantly, the sample size was small. Although there were 450 participants in total, each of the specific 15 respondent types only had 30 participants. Even with combining respondents into aggregate SEM level groups, the children with disabilities level still only contained 30 people. Therefore, the small—and disproportionate among SEM levels—sample sizes could affect the ability to obtain statistically significant results. Further, the sample wasn't randomly selected and all of the participants were selected from within or adjacent to the capital city, meaning no rural participants were included. These methods of participant selection, along with the small sample sizes, make it likely that the sample is not representative of the population of North Macedonia. Additional larger studies are required to improve the generalizability of the results of this study, both to North Macedonia as a whole and to external contexts.

The small sample size also prevented data from being disaggregated in important ways. While some questions were asked about both intellectual and physical disabilities separately, some were asked about disability as a whole. There is much evidence that the constructs of this model would vary by specific type of disability, even beyond the broad categorization of physical and intellectual impairments. For example, a study by Snyder et al. (2010) found workers with non-physical disabilities reported significantly greater levels of procedural injustice and subtle discrimination. Future studies would benefit from having enough participants to look at knowledge, attitudes, norms, marginalization, and stigma separately by physical and intellectual impairments at a minimum. The ability to examine the intersectionality of social norms with gender, age, and education would also provide important insights. Specific programs would want to further expand their sample and disaggregate by the specific disabilities of most relevance to them. The ability to analyze and report data by specific type of professional would also be beneficial and allow for better understanding of the specific communication intervention needs of the different stakeholders: heath workers who are often responsible for diagnosing disability, teachers who are charged with including children with disabilities into their classrooms, civil society organizations that provide much needed social services, and government representatives who are responsible for establishing child friendly policies.

This study is also limited in that it relies on self-reported data, which was not externally validated. Self-reported data cannot be independently verified, which means the responses to the questions must be taken at face value. This type of data collection is subject to bias, as participants might feel the need to respond in a socially acceptable way or participants may provide answers without fully understanding the questions. Respondents might also not be able to recall their experiences accurately. To improve data validity, an observation component could be added to verify treatment of children with disabilities.

Missing data also affects the study. Most notably, neither children with disabilities nor children without disabilities were asked the norms questions. The questionnaire was long, because it was testing many ways of measuring the constructs, and pretesting showed a great need to shorten the tool to accommodate the needs of children. Given the complexity of the norm's questions, and the struggle of the children to understand them during pretesting, this set of questions was removed from the children's questionnaire. As a result, we are not able to discuss the normative factors from the children's perspectives, which has two implications. First, it reduces the already small sample size for analysis of norms and discrimination, limiting generalizability. Secondly, it diminishes the ability to center the voices of those impacted, which as previously stated, is critical in research with marginalized populations. It is imperative that a simplified way of measuring norms, of which children are capable of comprehending, is developed.

Finally, this research is able to make broad recommendations on the value of multi-level communication interventions that cut across the SEM to address stigma and discrimination among children with disabilities. However, it is not designed to make claims about types of interventions that may be more effective than others, except to point to the relevance of including children with disabilities themselves and addressing knowledge, attitudes, and normative factors that impact the behaviors of professionals charged with protecting these vulnerable children.

CONCLUSION

Global conversations around disability are improving the ideological framework that guides national policy and legislation to protect the rights of children with disabilities. However, North Macedonia, like many countries, has focused too much on creating systems to deal with inequities faced by children with disabilities and their families, without adequately addressing the knowledge, attitudes, norms, and practices of those who make the systems run. Future work needs to take a more holistic perspective, with attention paid to stakeholders at all levels of the SEM. With improved, more systematic research and employing comprehensive communication strategies, it is likely that the rights of children with disabilities can be respected and their treatment improved.

DATA AVAILABILITY STATEMENT

The datasets generated for this study will not be made publicly available. The consent and assent forms indicated that the data would not be shared publicly.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Drexel University Institutional Review Board and Health Media Lab. Written informed consent to participate in this study was provided by all adult participants. Child participants gave verbal assent to participate, with written consent provided by their legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

SCS, SS, and KK contributed to conception and the design of the study, trained and oversaw the local research agency, and provided technical assistance throughout data collection. SCS and SS organized the database. SCS, SS, and NM performed the statistical analysis. SCS and NM wrote the first draft of the manuscript. All authors contributed to manuscript revision and read and approved the submitted version.

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