

Black Community Health Advocates in Ontario: A Look at Health Policy Engagement From the Ground Up

Défenseurs de la santé de la communauté noire
en Ontario : regard de fond en comble sur la
mobilisation des politiques de santé



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Abstract

Study objectives: Disproportionately negative pandemic outcomes, lack of race-based data collection and poor engagement of Black communities in policy decision making have been widely documented for Black Canadians. We examine this to understand how formal public engagement processes might be more inclusive of Black peoples to inform more responsive policies.

Methods: The study employed an asset-based lens to examine how Black communities have engaged in health policy and advocacy in Ontario. In-depth interviews were conducted with eight participants who self-identify as Black, recruited using purposive and intensity sampling to (1) identify *information-rich* cases, including people who have been at the forefront of high-impact work in this space and (2) participants whose mission and mandates represented diverse approaches and sub-populations.

Results: Our findings suggest that while Black community advocates face systemic and contextual barriers, they also embody deep and multifaceted knowledge, training and experience, which inform the rich ways that they approach advocacy.

Discussion: Despite its Ontario focus, this study adds breadth and depth to the existing literature on health policy and historically marginalized populations, offering broader lessons for policy makers across jurisdictions. Our findings encourage policy makers to better recognize, make space for and cultivate fertile advocacy foundations, cultural knowledge and community-driven systems already present in Black communities.

Résumé

Objectifs de l'étude : Les résultats disproportionnés négatifs de la pandémie, le manque de collecte de données fondées sur la race et la faible participation des communautés noires à la prise de décisions politiques ont été largement documentés pour les Canadiens noirs. Nous examinons cette question pour comprendre comment les processus officiels de participation du public pourraient être plus inclusifs pour les personnes noires afin d'éclairer des politiques plus réactives.

Méthodes : L'étude a fait appel à une approche fondée sur les atouts pour examiner la façon dont les communautés noires se sont mobilisées dans les politiques de santé et la défense des droits en Ontario. Des entrevues approfondies ont été menées auprès de huit participants qui se sont identifiés comme étant noirs, recrutés à l'aide d'un échantillonnage ciblé et intensif pour (1) identifier des cas riches en information, notamment des personnes qui ont été à la pointe d'un travail à fort impact dans ce domaine et (2) des participants dont les missions et mandats représentaient une diversité d'approches et de sous-populations.

Résultats : Nos constatations suggèrent que, bien qu'ils soient confrontés à des obstacles systémiques et contextuels, les défenseurs des droits des communautés noires incarnent également une connaissance, une formation et une expérience approfondies et multiformes, lesquelles façonnent la richesse de leurs approches pour la défense des droits.

Discussion : Malgré sa focalisation sur l'Ontario, cette étude ajoute de la profondeur et de l'ampleur à la littérature existante sur les politiques en matière de santé et les populations historiquement marginalisées, offrant des leçons plus larges aux décideurs de toutes les provinces et territoires. Nos constatations encouragent les décideurs à mieux reconnaître, à faire de la place et à cultiver la base de la défense des droits, les connaissances culturelles et les systèmes communautaires déjà en place dans les communautés noires.

Introduction

The COVID-19 pandemic illuminated the disproportionately negative health outcomes experienced by Black Canadians in both ordinary and emergency situations. This includes increased risk of contracting COVID-19, higher death rates and greater negative economic impacts as a result of pre-existing health disparities (African-Canadian Civic Engagement Council and the Innovative Research Group 2020; Amin and Bond 2020; Dei and Lewis 2020; Derfel 2021; Etowa et al. 2021; Etowa and Hyman 2021; Knight et al. 2021).

The alarm and high-profile nature surrounding the global pandemic converged with the global protests following the police killings of George Floyd and Breonna Taylor, expanding the appetite for engagement with Black communities across sectors and institutions – including the health policy sector. It is important to note that several critical conversations and important advancements have been made as a result of this season of increased engagement (Harris and Marcucci 2023; Thomas et al. 2024; Yeo and Jeon 2023). However, many of the underlying issues are yet to be adequately addressed, including a broader failure to address the social determinants of health in Black communities (Datta et al. 2021; Iroanyah and Cyr 2020; McKenzie 2020; Mensah and Williams 2022; Siddiqi et al. 2021), a historically poor track record of meaningfully engaging Black communities in health policy decision-making processes and a broader lack of disaggregated race-based data collection at all levels (municipal, provincial and federal) (Dhamanaskar et al. 2024; Glimmerveen et al. 2019; Polletta 2016). Among these underlying issues includes a lack of awareness and/or attention within the literature to the unique ways in which Black communities mobilize, advocate and lead change processes. These insights, however, are critical to the success of any aims to ethically and meaningfully engage Black communities in health policy decision making and change processes.

As such, in this paper, we examine how health policy makers might refine and reform their public engagement processes to increase the representation of Black people. In so doing, we take a ground-up approach and focus on the narratives of individual Black community leaders in Ontario, with the aim of understanding how they have engaged with and impacted health policy processes. These narratives highlight a plethora of issues; however, in this paper we focus specifically on 1) the personal and professional pathways that led these Black leaders to this work; 2) the nature of their leadership styles and approaches to advocacy; and 3) experiences and challenges while engaging with policy and decision makers. We conclude this paper with a discussion about the policy implications of our analysis, including the need for health policy decision makers to transform their public engagement efforts with the unique capabilities, approaches and needs of Black community leaders in mind.

Methodology

The theoretical and methodological choices for this work were driven by a desire to centre Black community voices in policy discussions and, by extension, challenge the circular and reductionist narratives about gaps and deficits in the Black community that often prevail in public discourse. We took a “critical qualitative inquiry” approach to this work (Denzin 2017: 8), and our data collection methods included semi-structured in-depth interviews with eight participants who self-identified as Black and engaged in public-facing work as health leaders and advocates in Black communities in Ontario. As Denzin (2017) describes, a critical qualitative inquiry approach involves unsettling traditional research by centring marginalized voices, using inquiry to reveal sites for change and activism and acting as a bridge between academic critique and policy change. In line with this scholarly tradition, our work

aims to “celebrate community, to experiment with traditional and new methodologies [and] with new technologies of representation” (Denzin 2017: 15). The theoretical framework that has guided our research is informed by Yosso’s (2005) conceptualization of “community cultural wealth” (p. 69), which challenges epistemological norms and assumptions to amplify community-based ways of knowing and doing. Yosso’s (2005) approach draws upon the counternarratives of historically marginalized communities to challenge deficit narratives by highlighting the cultural wealth, strengths and skill sets that often go unrecognized. These forms of cultural wealth (i.e., aspirational, social, navigational, resistant, familial and linguistic capital) emerge from wells of knowledge that are filled by intergenerational and community-based transfers, contemporary lived experiences and determination in the face of hostile systems and environments (Yosso 2005). This framework underpinned our analytic approach, which leans upon asset-based theoretical models that move us toward an appreciative approach to understanding Black issues, communities and leaders (Lamm et al. 2017; Yosso 2005).

For our data collection, we employed a purposive and intensity sampling strategy (Patton 2001) to recruit research participants for this study. This involved directly recruiting a focused set of “information-rich” cases that manifest the phenomenon in question “intensely” (Marshall and Rossman 2010: 105, 111), including people who have been at the forefront of high-impact work in this space. We also made an effort to recruit participants whose organizations/networks represented a diversity of approaches and sub-populations served. Our inclusion criteria required that the participants self-identified as Black and engaged in public-facing work as grassroots or organizational leaders in Black communities and/or health advocacy spaces in Ontario. As such, most participants were already known to us because of their public profile garnered through doing this work. Our semi-structured interviews were 60 to 90 minutes in length and took place in the summer and fall of 2021. These interviews were recorded, transcribed and analyzed thematically using an interpretive analytical approach (Denzin 2017). The project was approved by the McMaster University Research Ethics Board (Project no. 5482).

As critical and interpretive scholars, we recognize the importance of making note of our positionality in relation to the identities and experiences of our research participants and the overall focus and orientation of our research. Both authors of this paper identify as Black-Canadian women, with ancestral connections to the Southern Caribbean and East Africa. We both have past and continuing connections to African/Black community organizations and seek ways of bridging academia and community through our work. Being an *insider* in relation to our respondents came with many advantages in the interview process (e.g., ease of access, trust, racial and cultural concordance). However, we recognize that as academic researchers, we are still implicated in and affected by enduring power imbalances that exist between academia and historically marginalized communities, and worked to acknowledge and navigate this relational and ethical in-betweenness (Razack 2022) throughout the research process.

Results

Personal and professional pathways into this work

Many of the Black community advocates and leaders in our study were quite diverse, not only in their organizational mandates as it pertains to whom they serve, but also in their backgrounds. As such, they embodied cross-sector and interdisciplinary roots in areas spanning fields like medicine, natural sciences, community development, economics, creative arts, manufacturing and psychology. When we asked our participants to define the population that they serve, most were quite emphatic about centring the Black community. However, it should be noted that all of the participants were keenly aware of the fact that Ontario's Black communities were not monolithic and were quite diverse in culture, ethnicity, language, origins and, thus, needs. As one community leader noted:

I serve those who are oppressed in similar ways to me, but I don't think we're necessarily of one community. So, when we're sitting here in the Canadian context – I think we serve diverse Black communities who because we look the same, we're oppressed by the same anti-Black racism; and so, the work that I do helps them. I am definitely learning about each of our communities.

As such, some of the leaders also chose to focus their advocacy efforts on sub-populations based on particular intersections, such as age, ethnic group or health profile (e.g., specific chronic or genetic diseases). At the centre of their areas of focus was always a deep commitment to getting at the roots of health disparities and addressing systemic gaps.

How our participants came to the work of community health advocacy also varied greatly. As one participant stated, their interest in advocacy work came from their lived experience as a Black person. This participant came from a natural sciences background but studied at an institution that emphasized a critical and Black-centred approach. As such, they were able to adopt a nuanced and interdisciplinary approach to thinking about health disparities at the intersection of race. Another health leader was inspired to advocate for the health of Black communities through a convergence of factors, including an interest in understanding how social planning can inform responses to acute and ongoing social problems. As they developed more expertise, they began to see the ways in which race would intersect with various social determinants of health and was intrinsically linked to disproportionate outcomes for Black communities. Moreover, they observed both the redundancy in various interventionist programming and the inefficiencies of existing top-down approaches. This inspired them to find new and more efficacious ways to address these structural problems.

For others, their entry point into the health advocacy space was rooted in personal experiences in healthcare institutions. These experiences often included bearing witness to traumatic events where themselves, a loved one, or community member did not have their medical, physical or mental needs adequately met. This exposed the structural nature of racial gaps and power dynamics in the healthcare system, which inspired their interest in

serving others through advocacy. As one participant shared, they had often observed racially disparate treatment in their capacity as a healthcare worker, stating that “healthcare was [currently] designed to serve White Canadians.” In these ways, the participants were often driven to become advocates through lived experiences that provided them with a critical, deeper and more intimate understanding of systemic gaps beyond their academic training.

Many of our participants “fell into” or came to the work of community advocacy organically, building relationships with like-minded people committed to instituting systemic changes that would disrupt the healthcare space. In so doing, they combined their passion with their cross-sector and interdisciplinary educational training and experiences to “build and grow on the job,” united in the goal to, as one participant described, “secure the lives of Black people.”

Community-based leadership approaches to health advocacy

In our discussions with participants, they also outlined some central ways they engaged with their advocacy work. First, many described that their advocacy approaches were rooted in Afro-centric principles that were grounded in African/Black ways of knowing – a collectivistic and humanistic leadership style that is anchored in service to and building trust with the broader community (Airhihenbuwa 1995; Penceliah and Mathe 2007). This included a deep engagement with communities to closely listen to their needs and working *with them* to create intervention strategies. As one participant stated:

What we do is essentially listen very, very closely to what community is saying and identifying its challenges and then work with community to build a vision for how we address those situations, whether it be mental health, chronic disease, or how to address [broader] social determinants of health. And then our job is to mobilize the skills, tools, and resources to work with [the] community to implement interventions and do it at scale.

Second, integral to the nature of this advocacy work is a deep sense of respect and accountability to the communities that they serve, which have entrusted them with their stories and needs. This accountability also included working diligently to hold formal institutions accountable when they would make promises or aim to partner with Black community organizations. Third, we found that the nature of the work that these health leaders and advocates engaged in was quite diverse and complex. At the time of interviewing, much of the work called for these leaders and their organizations to support Black communities in more acute and emergent situations, such as the global pandemic. Advocacy in that case could include but was not limited to addressing pandemic-induced challenges, such as food and housing insecurity, or providing and connecting community to mental health services.

This work was in addition to the administrative labour required to keep these organizations running – often on shoestring budgets. As such, the work of these community

advocates was quite onerous. One participant described the multifaceted nature of their advocacy work as “triaging,” juggling and prioritizing efforts between acute, urgent needs in emergency situations and those that were organizational, programmatic and long-term.

My day-to-day looks different. Every day is different. A lot of our work right now is focused on mental health for children and youth. And then, a lot of it is focused on COVID, so my personal day-to-day is filled with trying to think strategy, it’s trying to deal with operational things – whether it be HR things or budgeting, as well as trying to move forward on our programmatic commitments and getting work done. So, my brain is often kind of split amongst those three kinds of things, all at the same time and trying to make it work ... That’s exactly what we have to do; triage it, every day.

At other times, advocacy work was shaped by broader goals that were more systemic and political in nature and were aimed at addressing the broader social determinants of health that contribute to racial health disparities. In addition to maintaining existing administrative duties and acute needs, this kind of advocacy aimed to achieve systems change and often required engaging in various forms of research and liaising with formal policy channels. Engaging with formal policy makers often involved encountering additional barriers and the need to navigate inequitable power dynamics and structures. This tension was captured by one of our participants who expressed the following:

Look, nobody is going to come to rescue us, so we have a responsibility to do something about it. And it’s challenging because the power lies somewhere else, and the responsibility lies somewhere else.

This participant went on to explain that they saw their policy engagement work as an effort to try to close the gap between those who have power and those who take responsibility to take action on these issues.

Experiences engaging with policy and decision makers

The Black community leaders we spoke with explained how the ways in which they interfaced with health policy and systems leaders were multidimensional and quite varied in terms of initiation, process and outcome. One participant described their organization’s experiences with health policy makers by expressing, “sometimes we convene or sometimes we get convened.” Leaders spoke about systems-level work as something that required skill and savvy, including an understanding of where the levers of change were and how best to mobilize community voices and resources to push against these levers.

You can't just jump into a meeting with politicians you know? We really have to have those spaces of organizing and sharing ideas and coming to a consensus about what our approach is and making sure that we're creating space for dissenting voices.

The navigational capital (to borrow from Yosso's 2005 model) demonstrated by the respondent above is one that was described by multiple participants as a form of knowledge that was built and passed down through intracommunity and intergenerational transfers and mentorship.

While many of the leaders we spoke with displayed an adeptness and effectiveness in navigating health advocacy processes, they also spoke at length about the wear and tear and the obstinate challenges they encountered while doing this work. For example, participants described the ways in which they would have to perform arduous educational labour in their efforts to engage with policy makers to achieve changes like improving systemic access to medical care for Black communities. As one health leader articulated,

I find that this role, we call it advocacy but it's also education because there's this narrative in Canada that racism doesn't exist here, and we've been accused over and over that [engaging in work that addresses the issue of race in health] is racist and divisive in [and] of itself. So, the work sometimes becomes, first of all, proving why we're having this conversation, and then forcing people to acknowledge anti-Black racism in the healthcare system and take accountability for that and change it.

In these ways, the advocacy work of the participants often pulled them in many different directions, summoning them to draw on their varied expertise, experiences, training and members of their organizational teams to manage the array of demands. While this speaks to their effectiveness and ingenuity as leaders, the gymnastics involved in this line of work also takes a psychic and physical toll – especially on people who are already stretched and experiencing these same structural barriers in their personal lives.

It is also important to note that the participants' advocacy was often outside of traditional or mainstream institutions, pathways and organizations. This means that their labour was more often than not offered voluntarily in an unpaid or marginally paid capacity. As a result, participants shared that they often lacked the mental, physical and particularly financial resources to carry out their policy advocacy to its fullest extent. As one participant described, the advocacy work they engaged in was most often “off the side of their desk” in addition to other personal and work commitments. Therefore, many of our participants were often stretched quite thin and this impacted their ability to engage in policy conversations and processes to the extent that they would like. One participant stated:

Other groups who are more established will have staff and resources that just monitor policy, keep ahead of policy, get input into policy. We sometimes don't even have

the time to go to the meetings when they call a meeting to talk about policy. So, the very structure of [agencies serving Black communities] always start at a disadvantage because [we don't have the] time and the [infrastructural capacity or access] to get engaged before the policy actually gets written.

It is important to acknowledge and examine the systemic challenges and barriers like the ones described above by Black community leaders. However, it is also critical that we do not let this focus ensnare us in a trap that reinforces the framing of Black peoples and communities as perpetually lacking or without capital. Instead, we should be inspired by their ingenuity, rich skill set and the lengths that these Black community leaders have reached *in spite of* these challenges. Further, we should be motivated by the transformative possibilities if these barriers were to be removed.

Discussion

The narratives shared by Black community health advocates in Ontario provide a powerful call to action for health policy makers. One central implication is the pressing need to recognize the strengths, assets and capacities embedded within these community leaders. Their interdisciplinary perspectives, diverse personal pathways and cultural and community intelligence contribute a rich tapestry of insights that can significantly inform policy formulation. The leaders we spoke with shared a deep sense of responsibility and accountability toward their communities, but also a recognition of and frustration with the inequitable distribution of power that mitigates their capacities to drive the change their communities need. By acknowledging the deep understanding these leaders possess about their communities and cultures, and the participatory processes and systems of accountability that they call upon in their work, policy makers are better positioned to access this expertise to create policies that are culturally responsive, relevant and impactful.

The narratives of these advocates also shed light on the structural barriers that impede their meaningful engagement in policy processes. Not only do these barriers negatively impact the leaders, the implications also extend to less effective policies, poorer community health outcomes and ultimately detriments to broader public health. Providing adequate financial resources, sustained institutional support and meaningful pathways for engagement better position Black community leaders, and the communities they represent, to contribute critical insights to policy discussions and processes. Addressing these systemic obstacles not only amplifies the voices of these leaders, but also acknowledges their vital role in shaping policies that address health disparities and promote equity.

Perhaps the most critical policy implication drawn from this study is the imperative for health policy makers to learn from and equitably partner with Black community leaders in ways that demonstrate true knowledge of and respect for the cultural wealth and assets they bring to the table. These advocates have been able to foster trust and strong and responsive networks by employing community-based and collectivist leadership approaches. As such,

policy makers at all levels of government (municipal, provincial and federal) can refine and reform existing formal public engagement processes to increase the representation of Black perspectives and peoples. They can embrace the principles of deep community engagement, active listening and collaboration modelled by these leaders to develop more inclusive and impactful health policies. However, given the deeply entrenched and long historical processes that have created current structural inequalities, we contend that a paradigm shift is also necessary, as resolution requires policy responses that are specific, targeted and contextual. Benchmarks must also be established and monitored in partnership with, if not led by, Black community organizations who are already experts of the constituencies they serve. Nevertheless, critical to this is recognizing and valuing the work and expertise these leaders and groups already have and providing the sustained support, investment and platforms that clear the path for the work that they do.

Frameworks like “critical qualitative inquiry” (Denzin 2017: 8) and “community cultural wealth” (Yosso 2005: 69) are also important in shifting the attention of researchers and policy makers toward community-based skills and assets that might have otherwise been buried beneath a deficit framing and a hyperfocus on challenges, needs and gaps. This reframing challenges mainstream notions of public and community engagement that rely upon fragile foundations, such as moral or bureaucratic imperatives (e.g., equity, diversity and inclusion [EDI] mandates). Instead, it offers a more accurate representation of this work and its capacity to be a rich source of critical technical policy expertise. This is an opportunity for mutual benefit all around, as leaders benefit from greater support, policy makers benefit from technical expertise and communities benefit from policies that reflect their lived experiences and needs.

Conclusion

In this paper, we elucidated the narratives of Black community health advocates in Ontario, paying attention to insights that hold vital implications for health policy makers interested in meaningfully engaging Black communities in policy processes. Our exploration has also illuminated the structural barriers that hinder meaningful policy engagement for these advocates without losing sight of all they have managed to accomplish despite these barriers. Based on our findings, we posit that there is an urgent need for health policy makers to recognize, leverage and amplify the strengths, assets and capacities of Black community leaders to appropriately and effectively engage Black communities, reduce harm and begin to address health policy gaps. Central to this call to action is a need for race-based data collection and policy engagement that is Black-led and centred at the municipal, provincial and federal levels to facilitate targeted, effective and data-driven interventions that are reflective of the distinct ways that Black community leaders approach their health advocacy work. In order to ensure stability and sustainability, Black-led health organizations also need core operational funding rather than relying on the existing contingent and project-based funding models.

While our study underscores the transformational potential of equitably partnering with Black community leaders, we also challenge traditional forms of community partnerships and engagement that does so without addressing existing community assets and structurally produced resource constraints. By shifting from deficit-based approaches to a framework that recognizes community capital and wealth, these collaborations can drive equitable health policies that truly reflect the voices and needs of the communities they aim to serve. Ultimately, we affirm that centring Black community leaders in the policy making process is more than just a checkbox in an equity mandate. Rather, such work is invaluable for decision makers interested in critical insights that might help to break the vicious cycle of unresponsive health policies and poor health outcomes for Black communities.

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Black Community Health Advocates in Ontario

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