Developing Culturally Relevant Literature on Vaccine Hesitancy in Black Communities

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Abstract

During the COVID-19 pandemic, Black Canadians and Americans (BCAs) have experienced higher rates of infection and death than whites, in part, because of vaccine hesitancy. Rates of vaccine hesitancy were not significantly different between Black and white North Americans, but the issue is much more complex for BCAs because of racism, medical mistrust, and numerous other factors. Two major systemic factors must be addressed to develop culturally relevant vaccine hesitancy research: capturing the complexities of the issue in our data and recruiting Black participants to studies. This paper reviews the shortcomings of vaccine hesitancy research to determine how to address these gaps. Common themes in the literature reviewed were identified and categorised. It was found that in order to capture complex data, researchers should collect thorough demographic and regional data, and should conduct more small-scale, Black-focused studies. To facilitate more open and honest discussions, they should also collaborate with Black co-researchers, center personal and vicarious experiences with racism, and address the stigma associated with being 'anti-vaxx'. To increase the representation of BCAs in study samples, researchers must build mutual trust and respect with participants and should also consider offering virtual and multilingual options for study participation. This guide has the potential to aid researchers in collecting less aggregated data on vaccine hesitancy that is more reflective of the values, beliefs, and concerns of BCAs, so that we can better support the health of the community.

Keywords: COVID-19, African Americans, African Canadians, medical racism, medical mistrust

Introduction

The COVID-19 pandemic has exacerbated existing racial and socioeconomic disparities in healthcare. Black Canadians and Americans (BCAs) have experienced higher rates of infection and death than whites due to several social-structural factors, including vaccine hesitancy (Cénat et al., 2022; Greenwood & MacDonald, 2021). Yet, rates of vaccination and vaccine hesitancy are not significantly different between Black and white North Americans (Cénat et al., 2022). This has allowed members of both groups to be labelled broadly as 'anti-vaxxers', an umbrella term which describes anyone who has questions or concerns about the COVID-19 vaccine (Newman et al., 2022). However, this stigmatization further alienates those who already belong to marginalized communities and who may have legitimate hesitations about getting vaccinated. Acknowledging these individuals is vital in developing effective approaches to increasing vaccination rates in these communities. Thus, it is important that we examine the structural differences between the contributing factors for vaccine hesitancy among Black and white Canadians and Americans.

The link between the avoidance of preventative healthcare, like vaccines, and medical mistrust is well documented (Jaiswal, 2019). Medical mistrust is a type of cultural mistrust, defined as the mistrust by Black people of whites and white-dominant systems due to the impact of historical racism and oppression (Moon, 2017). It is a concept that arose in clinical psychology and psychiatry and, at the time, was considered pathologic. Though with the continued pervasive of racism in Western society, we no longer consider it such. It is a rational survival mechanism for Black people to avoid further discrimination in environments that they find threatening, such as educational and medical institutions. Medical mistrust is especially complex because of the role historical and current incidences of medical racism in North

America play. Even after slavery was abolished, Black people were essentially treated as lab animals in countless cases, like the Tuskegee Syphilis Studies (Jaiswal, 2019), and were excluded from medical educational institutions (Byrd & Clayton, 2001). BCAs continue to experience everyday racism when seeking healthcare; they are ignored, not taken seriously, dehumanized, and not given the same access to care (Mahabir et al., 2021). Unfortunately, medical mistrust has been shown to stop people of colour from seeking preventative healthcare such as mammograms, cancer screenings, and vaccines (Jaiswal, 2019). Thus, medical mistrust is a significant contributor to the decreased rates of vaccination we see among BCAs. However, there are numerous other important factors that often go overlooked in vaccine hesitancy studies, which have the tendency to group all BCAs together (Cénat et al., 2022). To capture meaningful data on vaccine hesitancy, not only must we examine the differences between Blacks and whites, but we must also disaggregate the data collected from within the Black community.

There are two major systematic issues pertaining to studies on vaccine mistrust among BCAs. The first is that there is frequently important information missing from surveys (Cénat et al., 2022). For example, the 5A (access, affordability, awareness, acceptance, and activation) and 5C (confidence, complacency, constraints, calculation of perceived risks and benefits, and collective responses) scales were developed to address the determinants of under-vaccination rates and their complexities (Newman et al., 2022). However, they aggregate several complex social-structural factors into one category and do not place the same importance on them as they do on individual choice. With how complex vaccine hesitancy is, we should be capturing more data regarding systemic barriers, perceived racism, and other social, community, structural, and vaccine-specific factors. More robust data will better inform how we can address these determinants and effectively increase vaccination rates among BCAs. The second issue is with

the recruitment of Black participants as they are severely underrepresented in vaccine hesitancy studies (Cénat et al., 2022). Of the studies included in their review of vaccine hesitancy research in Canada, Cénat et al. (2022) found that only 1.18% of the sample population were Black participants. If studies are this underpowered, there is no way of capturing the true feelings and opinions of BCAs, especially on the regional or community level. More must be done to address these shortcomings in future literature.

This paper will review research surrounding BCAs, medical mistrust, and vaccine hesitancy to answer two questions corresponding to the systematic issues discussed: 1) How do we capture the complexities of vaccine hesitancy in our data? 2) How do we increase the representation of BCAs in our studies? The answers will aid researchers in developing more culturally relevant literature which incorporates a better understanding and responsiveness to the values, beliefs, concerns, and barriers of BCAs.

Methods

Search Criteria

Literature was obtained through the McMaster University Online Library and Google Scholar using the following keywords: COVID-19, vaccine mistrust, vaccine hesitancy, Black community, medical mistrust, vaccination rates, Canada, and North America.

Inclusion Criteria

The population of interest is Black individuals from Canada and the United States (US) of America. The data included:

1. Studies that have collected data pertaining to:

    1. The likelihood of BCAs to receive the COVID-19 vaccine

    2. The number of BCAs that have or have not received the vaccine

3. Demographic information about BCAs that have or have not received the vaccine

2. Other suggestions from researchers or members of the Black community on developing culturally relevant research. Suggestions were not necessarily related to COVID-19, but to other preventative healthcare measures as well (ex. HIV screening and testing).

Categorisation of Data

Shortcomings, research failures, and suggestions were identified in the literature reviewed. Common themes were then found and used to create categories of criteria that should be considered when developing culturally relevant literature.

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Results

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Three primary studies (Bogart et al., 2021; Momplaisir et al., 2021; Moon, 2017) and three secondary studies (Cénat et al., 2022; Jaiswal, 2019; Newman et al., 2022) were reviewed to determine which aspects of vaccine hesitancy research could be modified to address the associated systematic and systemic issues. One major theme across the studies was that respect and cultural awareness made BCAs more comfortable in participating honestly and openly in discussions on vaccine hesitancy in order to collect detailed data (Cénat et al., 2022). Respect can be shown through financially compensating participants for their time and effort, through prioritising their privacy, or through the use of culturally aware language which addresses the impact of historical and current incidences of racism (Jaiswal, 2019; Momplaisir et al., 2021).

Tackling stigma and allowing for anonymity were also common themes among the literature reviewed. Participants should be able to engage anonymously in research and express concerns about the vaccine without being labelled as anti-vax (Jaiswal, 2019). Collaboration was also highlighted in the literature. Including BCAs at every step of the research, from recruiting to editing, helps to break down the power imbalance between researchers and participants, helping

the former to gain better insight into the community they are studying (Jaiswal, 2019). The major themes identified were used to create specific considerations which researchers in the field can use to develop culturally relevant research on vaccine hesitancy. These considerations were further divided by which of the two major systematic issue it addresses: a lack of complex data or an underrepresentation of BCAs in study samples. The categorised considerations were then compiled into a guide, written below, for future researchers to reference when designing their vaccine hesitancy studies.

Discussion

Capturing The Complexities of Vaccine Hesitancy in the Data

One major systematic issue which has been consistently identified among vaccine hesitancy studies is that several complex social-structural factors are often aggregated into single categories (Newman et al., 2022). This perpetuates the idea that all BCAs are motivated by the same beliefs and face identical systemic barriers, which is not reflective of the actual experiences of the community (Cénat et al., 2022). Following are considerations for future vaccine hesitancy studies which can help to address this issue.

Collect a Wider Range of Data

An intersectional approach to research ensures we are considering all aspects of a participant's identity. Reviews of vaccine hesitancy among African Americans found that major predictors included gender, age, income, education, household size, medical distrust, experiences of racial discrimination, exposure to COVID-19 myths and misinformation, concerns about side effects, and vaccine safety issues, mental health. (Cénat et al., 2022). They also found that certain regional factors such as how successful vaccination campaigns are in the area, how easy it is to get vaccinated, and stigmatization in that region also influenced vaccine hesitancy. An

intersectional approach to research ensures we are considering all aspects of a participant's identity. Capturing more detailed information will help to unpack the complexities associated with vaccine hesitancy and help to disaggregate data from Black participants.

Center Experiences with Racism

Studies show that individuals who experience everyday racism more frequently are less likely to engage in preventative healthcare measures like vaccinations (Jaiswal, 2019). A syndemic study investigating COVID anxieties among African Americans also found that concerns about police brutality were positively correlated with concerns about COVID and race-related COVID worry (e.g. being worried that COVID is like the Tuskegee Studies) (Momplaisir et al., 2021). Even though the racial injustices were not experienced firsthand, they still impacted the trust African Americans had in the medical institution. Therefore, it is important to survey participants on both personal and vicarious experiences of racism, as these are important predictors for vaccine hesitancy among BCAs.

Develop Studies with a Black Focus

Too few studies have been conducted exclusively among Black community members (Cénat et al., 2022). Studies done with only Black participants would allow for more specific and detailed data. It is important that both small-scale studies are conducted in addition to the typical large-scale ones. Smaller scale studies, focus groups, and case studies are necessary to develop a better understanding of barriers, facilitators, and normative beliefs about vaccines in specific communities in the US and Canada (Momplaisir et al., 2021).

Prioritise Collaboration

We must be inclusive, collaborative, culturally appropriate, humble, and respectful of Black communities. Co-researchers from Black communities should be involved in all projects

and at every stage of the research, including recruitment, data collection, and publication (Cénat et al., 2022). Without collaboration, we see a power imbalance between participants and researchers, a lack of consideration of participants' barriers (ex. childcare, transit, multiple jobs), and ideological differences on medical subjects. Researchers have suggested bridging the gap between scholars and community members by engaging them as co-researchers (Jaiswal, 2019). Participatory research builds trust and helps researchers and clinicians to gain better insight into the daily lives and medical understandings of the people they are trying to aid. The inclusion of people with lived experiences at all stages of research will help to facilitate open, honest, and trauma-informed dialogue, while addressing historical and ongoing injustices. Many people who have hesitations about receiving the vaccine also have social networks that share their concerns (Momplaisir et al., 2021). Some even implied that vaccine acceptors they knew were foolish for getting it. We need to identify trusted members of these social circles who can be part of the study and the facilitation of change. Working with faith-based organizations and community figureheads or hiring healthcare staff from the community is an effective starting point (Jaiswal, 2019).

Address Stigma and Emphasize Autonomy

BCAs may be hesitant to express concerns about vaccines in order to avoid being labelled as 'anti-vax' (Jaiswal, 2019). However, medical mistrust and vaccine hesitancy are well-founded due to past/historical atrocities and current incidences of discrimination. Safety concerns are also prevalent among those hesitant to get vaccinated (ex. the vaccine was rushed, didn't do enough studies) (Momplaisir et al., 2021). The goal of vaccine hesitancy studies and the dissemination of findings should be to respect the autonomy of BCAs and provide them with the information they

need to make informed decisions about their health. Thus, messaging about the vaccine by physicians and researchers should be respectful of participant and patient autonomy.

Increasing Representation

Another shortcoming of several vaccine hesitancy studies is the underrepresentation of BCA participants in studies (Cénat et al., 2022). Not only are these studies underpowered, but they are unable to capture the diverse array of experiences and opinions seen throughout the Black community. Following are considerations for future studies which can help to increase the representation of BCAs in vaccine hesitancy research.

Offer Virtual Options

Virtual interventions allow vaccine-hesitant individuals to inquire anonymously about the treatment before receiving it (Jaiswal, 2019). This may play an important role in recruiting BCAs, as members of the community may be hesitant to express concerns about vaccines in order to avoid being stigmatized and labelled as 'anti-vax'. Virtual options, like video conferencing, can also help reach BCAs who cannot make the time or travel accommodations to participate in studies. In this way, leveraging technology can give more BCAs the opportunity and incentive to participate in vaccine hesitancy studies.

Show Respect for Participants

Showing respect for the participants' contributions is vital in increasing the recruitment rates of BCAs (Jaiswal, 2019). For example, monetary compensation shows a participant that their time and effort are appreciated. We must also prioritize the confidentiality and privacy of the data collected and disseminate findings in an accessible and meaningful way (Jaiswal, 2019). Participants should be treated as stakeholders in the issue at hand and deserve to see the outcome

of the study they contributed to. Seeing the impact of said study results may get participants more involved in future studies as well.

Invest in Cultural Competency Training

Black participants in a study conducted by Bogart et al. (2021) reported that they were most trusting of information provided by healthcare and social service providers regarding the COVID-19 pandemic. They were less likely to trust information from other sources, such as elected officials, and were more likely to believe that healthcare providers would be honest with them. Studies also show that a healthcare provider's recommendation is one of the most important factors associated with vaccine acceptance (Momplaisir et al., 2021). This suggests that the solution to tackling COVID-19 vaccine mistrust should be provider-led. However, cultural mistrust is highly correlated with instances of perceived racial discrimination. A study conducted by Moon (2017) found that subtle racism had a unique impact on the self-esteem and emotional functioning of black Canadians. Because the racism someone may encounter in a medical or experimental setting is not always overt, microaggressions from healthcare professionals and researchers may play more of an important role in medical mistrust than has been previously considered. Therefore, cultural competency training should be considered necessary for those involved in vaccine hesitancy research. This will encourage the dissemination of scientifically accurate information from trusted figures who are also able to navigate culturally sensitive and informed conversations with participants. It also ensures that participants feel comfortable continuing to engage in the research.

Recruit in Multiple Languages

Even though more than a quarter of Black Canadians live in Quebec, a primarily French-speaking region, almost all research on vaccine hesitancy has been conducted in English (Cénat et al., 2022). A large population of BCAs are excluded from study samples simply because of a language barrier, so research conducted in other languages would increase the number of BCAs able to participate. In Canada, most of the Black population speaks English and French, but Creole languages, Somali, Amharic and Niger-Congo languages are also frequently reported to be mother tongues (Statistics Canada, 2019). Black people also make up the majority of Haitian speakers in the US (Dietrich & Hernandez, 2022). Hiring Black translators is another opportunity to include BCAs in the research process and building trust with the community.

Conclusion

To aid researchers in conducting more culturally relevant studies on vaccine hesitancy among BCAs, I reviewed the literature surrounding the topic and developed a guide to address two major systematic issues. The first, capturing the complexities of vaccine hesitancy in the data, can be accomplished primarily by collecting a wider range of information including demographical and regional data about the participants. We must also consider personal and vicarious experiences with racism, as well as the stigma associated with being 'anti-vaxx'. Developing more small-scale, Black-focused studies and prioritizing collaboration with Black co-researchers can also help to collect more accurate and culturally informed information. The second issue, increasing the representation of BCAs among study participants, can be addressed by considering virtual options and multilingual recruitment. It is also vital that we build and maintain trust and mutual respect with participants so that they feel comfortable engaging in research.

This guide could potentially be applicable to other marginalized communities as well. For instance, the Indigenous peoples of Canada also have a complex and growing medical mistrust and vaccine mistrust (Greenwood & MacDonald, 2021). Historically, Canadian settlers have stripped Indigenous people of their rights and have not allowed them to make decisions about their own lives. Vaccine policies are highly reflective of this which, in part, is why COVID-19 vaccination mistrust has also resulted in higher rates of infection and death among Indigenous people. Like Black people, Indigenous people need to be assured that the past will not repeat itself and it is important to disseminate accurate and culturally relevant information for the purpose of helping Indigenous individuals make informed decisions about their own health.

There are a few limitations to this research that must be considered along with the results. At this time, the COVID-19 pandemic is ongoing and opinions surrounding the vaccine are constantly changing. Thus, the literature I reviewed, as well as the guide I developed, may not continue to be applicable to vaccine hesitancy studies on this pandemic, let alone future ones. It is also important to note that members of the Black community may share an identity, but they are still individuals with their own thoughts, beliefs, and ideas. No amount of information we gather can reflect the needs of all BCAs, so the suggestions made in this paper may not work for everyone. Researchers must take this into consideration and be careful to avoid generalizations when designing culturally relevant research studies. Despite its limitations, this guide has the potential to aid researchers in collecting less aggregated data on vaccine hesitancy that is more reflective of the values, beliefs, and concerns of BCAs. We must learn from COVID-19 and build knowledge on vaccine hesitancy so that we know how to better support the health of BCAs in the future, whether it be during another pandemic or for the annual flu shot.

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