BUILDING A NETWORK: BLACK WOMEN'S VISIONS FOR ONLINE PEER SUPPORT AND ADVOCACY IN HEALTH CARE

BUILDING A NETWORK: BLACK WOMEN'S VISIONS FOR ONLINE PEER SUPPORT AND ADVOCACY IN HEALTH CARE

A Thesis

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To Black women everywhere for inspiring me to learn, create and accomplish.

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ABSTRACT

Black women have long traditions of peer support and self-advocacy that has been advanced by the current digital age. Social media and online platforms have become spaces where Black women share and connect with other Black women, and campaign for their own needs regarding health care access and navigation. Drawing on the findings emerging from a focus group discussion between six Black women that explored their experiences in Ontario based health care settings, this paper describes women's suggestions for increasing access to Black and women-centered virtual health-related support and advocacy. Findings reveal that despite being young, Canadian-born and university educated, anti-Black racism and sexism permeates the health care encounters of all Black women; that Black women engage in emotionally taxing labour to have their health care needs met; and that Black women's positive and challenging experiences inform their suggestions for support and advocacy online with other Black women. The women's visions for health care support and advocacy expose an urgency for race and gender specific online health care support and health care reform that acknowledges the legacies of Black patients and goes beyond structural competency.

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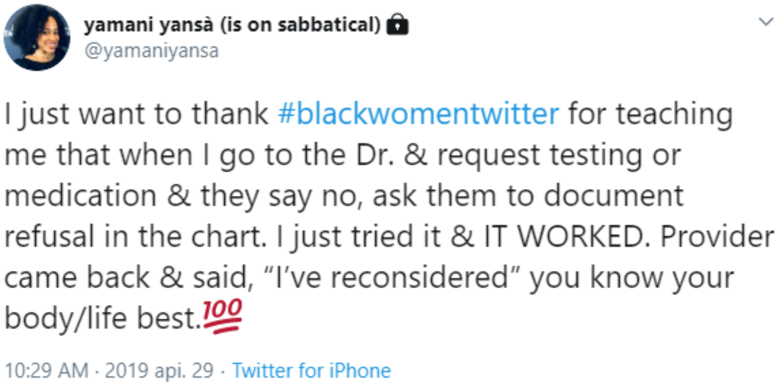
INTRODUCTION

As a Black female academic, I am indefinitely engrossed in the lives of Black women – not just their struggles, but their accomplishments, their intricacies, and their pursuits, too. My aim is to have that reflected in this research project. Although this project digs into the barriers Black women face in accessing and navigating health care, it also emphasizes their strength. The restructuring of existing systems that work against Black women are often disregarded and this is vindicated by the 'resilience' of Black women. Embedded in this resilience are the ways Black women have supported themselves and each other when systems work against them. When Black women experience race, gender and class oppression, their communities act as sources of support, creating cultures of resistance (Collins, 1990). There are many examples of Black women strengthening their communities through support, but the one I want to highlight strongly informs my interest in Black women and their relationship with the health care system:



yamani yansà (is on sabbatical) 🔒
@yamaniyansa

I just want to thank #blackwomentwitter for teaching me that when I go to the Dr. & request testing or medication & they say no, ask them to document refusal in the chart. I just tried it & IT WORKED. Provider came back & said, "I've reconsidered" you know your body/life best.💯

10:29 AM · 2019 api. 29 · Twitter for iPhone

Figure 1.

This tweet garnered great attention, being retweeted over 11,000 times and liked by over 29,000 accounts. The thread in response to the tweet consists of Black women talking about their negative experiences with health care providers and/or thanking Yamani for sharing this information. Black men and white women also responded, stating that they too will be using this tactic to advocate for themselves; while white doctors agreed with the motivation behind the tweet with some apologizing to Black women for having to be strategic about getting proper treatment. As a young Black person in a digital age, information about Black health being available online is of incredible value simply for reasons of access and exposure. In 2015, 90% of young adults (aged 18 to 29) and 65% of American adults used social media sites (Perrin, 2015), and in 2014, 80% of Internet users had sought health information online (Hether, Murphy & Valente, 2014). Social media platforms are expanding to include access to a range of topics, including health, health care and well-being. In addition to this tweet, the phrase "doctors are to Black women what police officers are to Black men" is a controversial phrase I have come across on social media platform, TikTok, which speaks to how current generations perceive the realities of Black lives and bodies (Kiki, 2020). The rise of the Black Lives Matter movement has increased an awareness about Black health and medical racism on social media, and having both formal sources and informal sources available while writing this thesis was important for presenting an academic stance, while also highlighting a highly personal stance.

This study explores the health care support needs of Black women in the context of access to everyday health care, highlights racism and sexism as they exist in Black women's health care experiences, and asks the question of what is needed on an online health-related support platform for Black women. In this study, racism is defined as an oppressive "system of structuring opportunity and assigning value based on the social interpretation of how one looks" (Crear-Perry, 2018), and sexism is defined as an oppressive system based on gender differences that involve "cultural and institutional policies and practices" and individual beliefs and actions (Shorter-Gooden, 2004). Stereotypes, discrimination, and bias are various manifestations of racism and sexism that are discussed (Shorter-Gooden, 2004). The research questions have been developed to explore the experiences of self-identified Black women in general health care navigation, and to provide a framework for the development of an online health care-related platform where Black women can support each other to navigate health care spaces.[1] For the purposes of this study, health care includes primary care such as interactions with family doctors, nurse practitioners, and other general health care providers, and interactions in community health centres, walk-in clinics, and student health services.[2]

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[1] For the purposes of this research, 'Black women' refers to women of African descent, recognizing that there is diversity within this population, coupled with the recognition that not all women from this ancestry identify with the term 'African American.'

[2] The terms health care provider,' 'health care professional,' 'clinician,' 'physician,' and 'doctor' are used interchangeably to represent those providing health care to patients.

THEORETICAL FRAMEWORK

Originally, intersectional feminism and critical race theory (CRT) qualified as appropriate theoretical frames to ground this work of exploring Black women's navigation of health care and they remained applicable in looking at how Black women can support and advocate for each other in these experiences. These theories would bring in the necessary considerations of how race and gender play out in Black womanhood. CRT began as a movement in law, exposing and challenging the practices of subordination enabled in legal discourse and institutions (Delgado & Stefancic, 2001; Ford & Airhihenbuwa, 2018). Understanding race as central to law and policy could be extended to other disciplines and could be used to explore and understand Black women's interactions in health care.

However, in conducting exploratory research into the origins of intersectional feminism and critical race theory, Black feminist epistemologies emerged as a grounding force from which Black feminism and intersectionality emerge as specific theories. For example, Black feminist thought, as a critical social theory, lays the foundation for Black feminist activists and academics to create theories, such as intersectionality, to exist in the ways they do (Collins, 1986; Patterson, Kinloch, Burkhard, Randall & Howard, 2016). Black feminist thought and intersectionality make room for gender and race without doing the work of separating them from their legal origins and proving how they could be applicable in health research. Additionally, I believe what critical race theory offers (for example, recognizing, understanding and then changing the social situations of Black folks, or understanding that society is racially driven and therefore unequal) is covered by Black feminist thought, while intersectionality incorporates the realities of multiple identity categories for Black women (Delgado & Stefancic, 2001; Hylton, 2012).

There is a long tradition of Black feminists (both academics and ordinary women) describing Black womanhood. In this paper, I highlight the work of Patricia Hill Collins and Kimberlé Crenshaw, labelling their contributions to Black feminist epistemologies and their influence in my research. Attention will be paid to Black feminist thought and intersectionality as two theories that are born out of Black feminist epistemologies. These theories work together to explain the Black female reality that is essential to my analysis of Black women's health care experiences and how Black women support each other to navigate health care. The evolution of knowledge into action is a critical tenet of Black feminism, and is therefore appropriate in a project involving Black women who narrate their experiences, both positive and challenging, and then work together to propose elements of a platform that could change the ways their Black women peers encounter health care (Patterson et al., 2016). This platform seeks to act as resolution, community and resistance. "As Black women, we see Black feminism as the logical, political movement to combat the manifold and simultaneous oppressions that all women of colour face" (Collective, 1983).

Black Feminist Thought

Collins (1989, 1989) defines Black feminist thought (BFT) as a means to operationalize it as both a way of knowing and a theory used to illuminate the lives of Black people, and women specifically. Born of out exclusion and marginality in racial and sexual movements for equality, Black feminist methodologies strive to center Black women's voices in analysis (Collins, 1986). For this reason, BFT is an oppositional knowledge that seeks to force its user to ask, "How does my work contribute to BFT's overall oppositional stance towards systemic, societal oppressions?" (Collins, 2016, p. 134). In answering this question, knowledge about the social work is developed to promote new practices and actions that disassemble the status quo (Collins, 2016). In Collins' work, she pays homage to Black feminist historians, authors and scholars and synthesizes their ideas, while demonstrating her own contribution to Black feminist thought. As self-identified Black feminists, it is necessary to look at these authors in my research as their own epistemologies originate from research on Black women. Their way of knowing is inextricably tied to their identities as Black women, just as my way of knowing is tied to my identity as a Black woman. BFT is a self-defined way of knowing acquired through "living, surviving and thriving within multiple forms of oppression" (Patterson et al., 2016, p. 58).

Black feminist thought is defined as a collection of ideas that emphasizes a self-defined standpoint for Black women and should be argued as a workable theory for its operation in sociology, critical social science, law, and social work are undeniable (Collins, 1986; Collins, 1989). Collins (1989) clarifies that the term 'standpoint' is not meant to suggest it is shared by all Black women; rather it is meant to describe the plurality of Black women's experiences. The term is used across Collins' publications and is more thoroughly discussed in *the Social Construction of Black Feminist Thought* (1989) – it can be understood as the independent and deliberate interpretation or consciousness Black women have of their own oppression, and should be seen as bigger than a 'perspective.' It is important to use Black feminist thought as a way to rearticulate this standpoint because it is possible for more powerful groups to discredit oppressed groups' standpoints if they view them as a means to resist domination (Collins, 1989). Like other oppressed groups, Black women have not only developed original interpretations of their oppression but have done so by using alternative methods to create and authenticate knowledge itself (Collins, 1989).

Collin's (1989) 'standpoint' is significant in understanding the methods that can be operationalized to display use of Black feminist thought. Collins (1989) leans into Peter Berger and Thomas Luckmann's method for clarifying the relationship between Black feminist thought and the Black women's standpoint by suggesting that knowledge exists on two levels: "The first level includes the everyday, taken-for-granted knowledge shared by members of a given group … Black feminist thought, by extension, represents a second level of knowledge, the more specialized knowledge furnished by experts who are part of a group and who express the group's standpoint" (p. 750). These levels of knowledge are dependent. BFT articulates the first level by communicating a standpoint, or consciousness, that already exists, demonstrating that everyday Black women produce specialized knowledge. When Black women see their subjective knowledge as specialized, they are offered a unique view of looking at themselves and other Black women and assign value to their subjective knowledge. This redefining and rearticulating can be used as a tool of resistance to multiple forms of domination (Collins, 1989). Research processes with Black women by Black feminists should be rooted in these levels of knowledge. Collins (1989) describes, at length, the way in which Black feminist thought scholastically advances the natural and ordinary philosophies of Black women. In my research, this is important. I only want to be the presenter of knowledge discussed by Black women; to share the information Black women already know and have taken time to share with others, taking into account how the theory discusses knowledge mobilization.

Along with Collins' (1986) basic working definition of Black feminist thought above, she provides a list of assumptions that underscore this definition. For one, it is important to consider the historical, epistemological, and material circumstances that shape the producers of Black feminist thought (Collins, 1986). Living as a Black woman is a prerequisite for producing Black feminist thought because of the ways in which knowledge is produced and validated within Black women's communities. Histories of slavery, oppression, and colonization, for instance, are shared. While asserting this, Collins (2016) articulates that BFT is not the property of Black women, as allyship with groups with similar histories of struggle is important in exposing domination in systems; however, Black women have the highest stake in advocating for BFT as oppositional knowledge and so Black women ought to be the "agents of knowledge" in the production and consumption of BFT (p. 140). This idea lends into the second assumption: Black feminist thought assumes Black women have unique perspectives about their experiences that can be shared among them as a group. The third assumption posits that Black women are not a homogenous group; that there is much diversity in age, sexual orientation, class and other social categories, and so though there are common themes in the Black women's standpoint, these themes will be experienced and reflected differently (Collins, 1986). When feminists or sociologists speak about women, often making observations, generalizations and interpretations, Black feminists ask the question of "which women?" (Collins, 1986, p. 27). Black feminists are very clear about which women they represent and make conclusions for, and considering the recognition of diversity, are less likely to make generalizations. Though connectedness to a group is recognized as important, the individual experiences of women are not systematized into assumptions of sameness (Patterson et al., 2016).

In addition to Black Feminist Thought's three assumptions, there are also three key themes: the interlocking nature of oppression, the importance of self-definition and self-valuation, and the importance of redefining culture (Collins, 1986). Interestingly, different Black feminist scholars highlight different key themes in their work in different ways and, sometimes, use different terms. Embedded in Collins' understanding of the interlocking nature of oppression is Kimberlé Crenshaw's (1989) theory of intersectionality. Black feminist thought speaks to the interactive nature of race, gender and class; arguably one of the most imperative contributions of

Black feminist thought, as said by Black feminist, Barbara Smith (1983) (as cited in Collins, 1986). Managing the effects of interlocking systems of oppression incidentally creates the unique standpoint that makes up BFT. Beyond this, the interactive nature of oppression is important because it focuses on the links between race, gender and class oppression and centers this interaction as the object of study.

Black female self-definition and self-valuation are significant themes within Black feminist thought and necessary for Black female survival (Collins, 1986). Self-definition involves the process of challenging stereotypical images and interpretations of Black womanhood that dehumanize and exploit Black women; it is the act of actively rejecting and resisting the assumptions made about them by external, likely more powerful groups, and allowing Black women to describe their own reality, validating Black women's power. Instead of internalizing the "psychological oppression" that comes with being stereotyped, self-definition and self-valuation highlight how to embrace assertiveness and use this quality in survival (Collins, 1986, p. 18).

Lastly, Black feminist thought can further be characterized by efforts to redefine the significance of culture. Culture is a broad and subjective concept. Collins (1989) seems to frame culture as subjective knowledge, traditions, and meanings. To me, culture is conceptualized as the ways people go about projecting their identity; this includes traditions and customs, knowledges, expectations, boundaries and norms, but also language, and stories told amongst a group of people who share an identity. Culture was not an area of interest I thought would be relevant in this research because I neglected to see how Black women creating their own informal methods of support is influenced by culture or is a form of culture. Black feminist research reveals many "unexplored areas of the Black female experience," such as areas of social relations where Black women "create and pass on self-definitions and self-valuations essential to coping with the simultaneity of oppression they experience" as a result of culture (Collins, 1986, p. 21). This reinforces the importance of exploring support and advocacy, for Black women have traditions of creating community and informal spaces to reflect, share and support each other. This idea of Black women creating and passing on definitions and valuations is especially important in collecting suggestions for an online platform that seeks to help Black women offer ways to better navigate health care and support each other.

Crenshaw's Theory of Intersectionality

Collins' articulation of Black feminist thought lends into Crenshaw's theory of intersectionality. Crenshaw is known for advancing intersectionality in the years following the publication of Collins' 1986 *Learning from the Outsider Within: The Sociological Significance of Black Feminist Thought.* Black feminist understandings that seek to address interlocking oppressions have long existed, but Black feminists have been excluded from spaces that would allow them to put their understandings into action. Crenshaw changed this, and therefore made a significant contribution to feminist scholarship. Intersectionality tackles the neglect of difference and diversity in traditional, white, Western feminism, and ensures the longevity of feminism as it would be inclusive if intersectionality is taken up (Davis, 2008). In *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Policies*, Crenshaw (1989) writes specifically about anti-discrimination law and how the legal system "frame[s] and interpret[s] the stories of Black women plaintiffs;" however, the analysis outlines Crenshaw's understanding of intersectionality that expands to many areas where Black women encounter race and sex discrimination (p. 141). Crenshaw's understanding of the ways feminist theory and activism, and antiracist policy exclude Black women, informs her of a widely used analysis of racism and sexism that uses a single-axis framework to look at race and gender separately. Intersectionality challenges this single-issue analysis. Though her epistemology is unique, coming from a legal perspective, Crenshaw is explicit about her ontology regarding the subordination of Black women in daily encounters in legal contexts, specifically anti-discrimination law, and social contexts, specifically those that pertain to violence against women of colour. Black feminist criticism and intersectionality develop out of an understanding that there is a tendency to understand race and gender as "categories of experience and analysis" that cannot co-exist, which Crenshaw refutes (Crenshaw, 1989, p. 139).

Crenshaw (1991) frequently uses the term "mutually exclusive" to explain feminist and antiracist theories and practices avoidance in looking at how sexism and racism interact in people's lives, positing that these experiences occur on mutually exclusive confines (p. 1242). To pin only the Black identity onto a Black woman to explain her experiences is to disregard the other violent experiences she encounters based on class and sex or gender. In an effort to center the experiences of Black women, who are theoretically erased in a series of systems, Crenshaw (1989) makes explicit how the operations of feminist theory, politics and tradition exclude Black women and therefore need to adopt and apply an analysis that considers the interactions of race, gender and class. Feminist theory cannot represent all women and exclude Black women simultaneously. Claims like "women are…" or "women believe" are misguided when they lean towards the thoughts, issues, and needs of white women and not marginalized women, too (Crenshaw, 1989). Feminist and antiracist discourses rarely take up intersecting patterns of racism and sexism, and "because of [Black women's] intersectionality identity as both woman *and* of colour, within discourses that are shaped to respond to one or the other, women of colour are marginalized within both" (Crenshaw, 1991, p. 1244).

Crenshaw (1989) suggests for feminist theory and politics to look to Black women's history to fill in the current gaps that make it unreasonable to claim representation of all women. The reality of Black women's experiences cannot be demonstrated by a theory that is told by white women who, but for gender, share many of the same cultural, social and economic characteristics as those of white men (Crenshaw, 1989). Additionally, traditional feminism consistently leaves out marginalized groups of women, as seen by transfeminism and womanist movements and their reconstructions of feminism to include more women (Koyama, 2003). For these reasons, traditional white feminism is not used to collect or analyze the data in this research project, as it holds no value for or to Black women. The ability to overlook a series of dimensions of identity that, for Black women, determine how they are treated in every interaction, is privilege. The need for Black feminist epistemologies and methodologies are clear.

Feminist users of intersectionality say it "promises … universal applicability," is useful for understanding and analyzing social practices, group and individual experiences, structures, "cultural configurations," and can be "employed by any (feminist) scholar willing to use [their] own social location … as an analytic resource rather than just an identity marker" (Davis, 2008, p. 72). Though its essentiality in feminist scholarship is evident, intersectionality is critiqued for its vagueness; some understand it as a concept or process, while others regard it as a theory (Davis, 2008). Crenshaw (1991) asserts that intersectionality is a "provisional concept linking contemporary politics with postmodern theory," connecting seemingly incompatible theories, and for this reason, intersectionality brings new lens to an old idea (p. 1244; Davis, 2008). For this project, intersectionality is used as a theoretical perspective for the way it persuades its audience of a particular ontology, one that looks at multiple dimensions from an intersectional lens. Intersectionality's ambiguity allows it to be useful to a broad audience (different disciplines, scholars, in popular culture). However, I do understand that not all scholars work from this open-ended theory concept and would prefer a guide on how to use intersectionality in their work. Additionally, the questions of which and how many identity categories should be included in an intersectional analysis and if it should be used as a tool to unearth exclusions or used a resource for empowerment are pitfalls of intersectionality, lending to its vagueness (Davis, 2008). Evidently, intersectionality leaves room for individuality and flexibility; it is both esoteric for specialists, and accessible enough for generalists.

The Interface between Black Feminist Thought and Intersectionality Theory in my Research

Collins and Crenshaw assign labels to long-existing concepts, both in feminist scholarship and in the Black community. Black feminists, like those who make up the Combahee River Collective (CRC), laid the foundation for the works of Collins and Crenshaw, who have redefined and reclarified feminist and anti-racist scholarship, as the CRC manifesto states it does of its politics (Collective, 1983). As the CRC did, Collins' and Crenshaw's work, as outlined above, actively combats racial, sexual, and class oppression (Collective, 1983). Additionally, their work highlights how traditional feminist scholarship has been limited in its depictions of Black women (Collins, 2016; Crenshaw, 1989).

Crenshaw (1989) and Collins (1986) agree that Black women have a unique view of oppression. Black women experience discrimination in ways similar to that which is experienced by Black men, being Black, and similar to that experienced by white women, being women. This intersection of being Black and a woman, however, activates a dual discrimination. Unlike Black men, Black women cannot depend on patriarchal notions of manhood to "neutralize the stigma of being Black," and unlike white women, it is impossible that their whiteness may refute the subordination of being a woman (Collins, 1986, p. 19). Racism, as experienced by Black men, for instance, determine the parameters of antiracist strategies; sexism, as experienced by white women, determine the parameters of the women's movement – these discourses that exclude Black women are limited as they fail to speak to the dimensionality of racism and sexism (Crenshaw, 1991). Crenshaw (1989) extends that Black women are only protected to the extent that their experiences of discrimination align with those of either of these groups. This seems to suggest Black women must conform to a type of discrimination that fits that which is experienced by white women or Black men; neither being fair, as they exclude a crucial part of identity for Black women. There is obvious agreeance on the Black women's unique standpoint by both authors.

Intersectionality is known for its vagueness and open-endedness, and while some see this as a pitfall, Davis (2008) sees the vagueness of intersectionality as a strength, citing that it "initiates a process of discovery" (p. 77). I would argue that where intersectionality may lack, Black feminist thought fills gaps and answers epistemological and methodological questions. Additionally, intersectionality has a history of being a basis for "mutually beneficial collaboration between theoretical projects," providing additive approaches to conceptualizing multiple identities (Davis, 2008, p. 74). Using this combination of theory in data collection means collecting narrative accounts of lived experience using participatory methods, while being critical about the race, gender and class identities of participants. For example, it would not be enough to simply recruit a group of women (with attention strictly to gender) or to recruit Black people (with attention only to race) when operationalizing BFT and intersectionality. Both BFT and intersectionality honour the difference and diversity that is present in a group of university

Black women. Also, both make comparisons of Black womanhood to Black manhood and white womanhood, which make for clear articulations of how combinations of gender and race identity markers are important to consider in recruitment of Black feminist projects.

Likewise, in data analysis, a feminist analysis would not have been enough to grasp the marginalization faced by Black women. BFT looks to gain a collective understanding of the Black standpoint, while simultaneously, reserving the right for women to have their own voice. In developing an online platform for Black female health rooted in support and advocacy, this is especially important. Additionally, both theories address the motives of racism, sexism, and classism in Black women's experiences, addressing the question of 'why' and pointing to the intersections of identities that make up Black womanhood. They also both contribute to the advancement of new knowledge that conceptualizes these multiple dimensions and identities. For this reason, I argue that Crenshaw's analysis in the context of legal issues translates well to other disciplines because, as Collins (2016) states, the power relations that form when race, gender and class oppressions intersect strategically exclude Black women from education, employment, and health care. I propose that BFT and intersectionality provide the basis from which to do a thorough investigation of Black women's experiences in health care as a consequence of these power relations.

LITERATURE REVIEW

To date, existing research on Black women's interactions in health care typically focuses on a specific type of health care (for example, cancer care or HIV care) with less attention paid to experiences of accessing general day-to-day health care (Davey, Kissil, Niño & Tubbs, 2010; Sangaramoorthy, Jamison, & Dyer, 2017). This remains true for social support research in the context of health care; research looks at the social support needs of Black women including those living with HIV (Warren-Jeanpiere, Dillaway, Hamilton, Young & Goparaju, 2017), Black women living with breast cancer (Coggin & Shaw-Perry, 2006), and Black women living with depression (Bronder, Speight, Witherspoon, Thomas, 2014), omitting support for non-specialized health care needs.

Primary Care

Primary care is not to be confused with primary health care. Canada has a primary health care framework, an approach that seeks to be responsive to community needs beyond the traditional health care system, and within this framework is primary care (Government of Canada, 2012). Primary care is defined as covering basic and general medical care, is typically delivered by family doctors and general medical practitioners and acts as first contact access for health needs (Canadian Nurses Association, 2005; Government of Canada, 2012; Starfield, Shi & Macinko, 2005). Health promotion, preventive care, such as general health screening and immunization, treatment of acute and chronic illness, and referrals to specialized services are met through primary care (World Health Organization, 2011; Government of Canada, 2012). Cooper's (2004) analyses of studies is based on the definition of primary care as the provision of integrated and accessible health care services by physicians who are responsible for the undertaking of health care needs in family and community contexts, with attention to developing alliances with patients. This description of primary care aligns with the definitions provided by the Canadian Nurses Association (2005), Williams, Massaquoi, Redmond, Chatterjee & James (2011) and the Government of Canada (2012), pointing to a standard and widespread understanding of primary care, yet, from my research, health literature rarely focuses on the area of primary care that looks at day-to-day interactions with family physicians and other general medical practitioners.

Bliss et al. (2004) conclude that less Black people than white people receive health care in primary care settings like doctors' offices, outpatient clinics and hospital emergency departments. Note that this study does not focus specifically on Black women, but does point to the Black population's absence in primary care settings. Likewise, though frequent primary care visits are associated with use of mammography, Black women receive less mammography than white women even when primary care visits are considered (Burns, McCarthy, Freund, Marwill, Schwartz, Ash & Moskowitz, 1996). Primary care visits are less likely to encourage Black women to get health screening and testing, which primary care is meant to facilitate, pointing to a racial disparity.

Canadian health care enables Black women to be beneficiaries of a "socialized" health care system; however, Black people, whether from Africa, the Caribbean, or born in Canada, are "unacquainted" with the Canadian health care system making it impossible to use effectively (Flynn & Taylor, 2009). In many ways, racism has been a part of the experience of health care for Black folks. Black patients have long been subjected to substandard care, discrimination, and stigma in health care, making fitting into and using the system more difficult (Wiltshire, Cronin, Sarto, & Brown, 2006; Flynn & Taylor, 2009). The literature presented in this review suggests that this estrangement stems from the continued discrimination Black individuals perceive in their interactions and the subsequent avoidance of health care as a result.

Research on Black Women & Health

Focus on certain populations and a lack of attention on the experiences of Canadian born, young and educated Black women

Much of the health-based research of Black women's experiences is grouped together with other racial, ethnic or gender populations (Bliss, Meyers, Phillips, Fryer, Dovey & Green, 2004; Ross, Lypson & Kumagai, 2012; Cuevas, O'Brien & Saha, 2016). As Flynn and Taylor (2009) argue, "the particularities of Black women's health issues are subsumed under that of Black people as a whole. Ethnicity is often conflated with race, and research that considers race and class ignores gender, sexuality and age as relational and mutually constituting forces" (p. 254). This highlights the lack of awareness that minority populations are heterogeneous and this paucity becomes more apparent in their disregard for Black female populations. Although research with large sample sizes can benefit from groupings in this manner, I have questions about the effectiveness of this approach when it comes to interpreting data that is aimed at elevating the particular experiences of Black women. Furthermore, it is important to note that while racism and racial bias within health care is well documented, as reflected in the ground breaking report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Nelson, 2002; Villarosa, 2018), there is little acknowledgement for how these effects are perceived by Black people and in particular, Black women.

As shown in *Every Woman Matters* and similar reports, research is laden with information about the ways low-income and immigrant Black women access health care and health information, while less is known about the challenges that Black women of higher socio-economic status (SES), or other privileged positions, face in access to health care and information (Williams et al., 2011; Sacks, 2017; 2018). Upon review of the current literature, it became evident that there is little focus on Black women who are young, relatively healthy, Canadian-born and/or university educated, who experience hardships in accessing and navigating health care nonetheless. This thesis seeks to add to the small body of literature that exists in this area and argues that Black women, regardless of class and immigration status, experience barriers to care because they are Black and female.

Barriers to Primary Health Care for Black Women – Addressing Race, Gender, Class

Barrier to Care: Misogynoir

Black women of all classes are vulnerable to the racist and sexist antipathy Black scholars call 'misogynoir' (Sacks, 2018). Misogynoir is a combination of the terms 'misogyny,' the dislike of women, and 'noir,' meaning Black, that is used to articulate the specific intersection of racism and sexism *for* Black women (Bailey, 2016). Like racism and sexism, misogynoir permeates systems and institutions and in the case of the medical system, pathologizes Black women's bodies and harms their health (Bailey, 2016). Assumptions about what is 'normal' often delegitimize the Black female body, and "these discourses of the normal body travel from science to society, reinforcing medicalized knowledge that is already culturally produced" (Bailey, 2016, p. 7). Bodies outside of the white, female body are seen as abnormal, creating a standard that excludes other bodies that would be measured against this norm. This white standard of health and normality contributes to substandard care for marginalized populations in the health system (Bailey, 2016). We see this has led to a mistrust of doctors by Black women, making the health care encounter of low priority or something to disengage from completely (Bailey, 2016; Burns, McCarthy, Freund, Marwill, Schwartz, Ash & Moskowitz, 1996).

Barrier to Care: Class is not armour

In her book, *Invisible Visits: Black middle-class women in the American healthcare system,* Tina K. Sacks (2017) argues that Black middle-class women are rarely studied in health inequality research and yet, similar to other research on health inequities experienced by poor, minority and immigrant populations, encounter stereotyping and discrimination in health care (Anwar, 2019). In an interview with UC Berkeley News (2019), Sacks states that it is assumed Black middle-class women do not experience bias or health inequality albeit “infant mortality rates for Black women with a college degree are higher than those for white women with just a high school education” (Anwar, 2019). Black middle-class women are an interesting group to research in that they are not poor, or “burdened” by poverty, but are “socially and economically vulnerable nonetheless” (Sacks, 2018, p. 1). Sacks (2017, 2018) asks the question of how race and gender, and the stereotypes, bias and discrimination associated with these identity categories, affect Black middle-class women’s treatment in health care settings. One answer is that SES does not erase the pervasiveness of misogynoir (Bailey, 2016). Black middle-class women interviewed by Sacks report that they, too, anticipate discrimination in their encounters with health professionals, and that this invisible barrier leaves them feeling as though they need to fight for legitimacy (Sacks, 2018).

This idea that SES provides little protection for health disparities is exaggerated by tennis star, Serena Williams’, experience after her Caesarean childbirth. Williams, who has a history of blood clots, details complications after delivering her daughter to which her medical staff were initially dismissive and therefore unprepared to manage her pulmonary embolism, the abrupt blockage of an artery in the lung caused by a blood clot (Williams, 2018; Villarosa, 2018). This flowery example disproves the belief that only low-income, uneducated Black women are affected by high infant and maternal mortality rates; maternal near-death experiences remain for Black women beyond class. Williams (2018) later wrote about her experience, highlighting Black women's increased likelihood of dying in or after childbirth and asserting that before Black women "bring a new life into this world, the cards are already stacked against them." Sacks' (2018) and Villarosa's (2018) research point to the structural and systemic inequalities that must be addressed to develop interventions that disable bias and discrimination via negative stereotypes about certain race and gender combinations. Still, it should be enough to know Black women are overlooked in health care without looking into whether they are educated or wealthy or not.

<u>Barrier to Care: Perceived Racial Discrimination</u>

Not surprisingly, Black individuals are more likely to perceive discrimination in health care encounters than their white counterparts (Cuevas, O'Brien & Saha, 2016; Ross et al., 2012). This perception has effects on quality of care and communication between patient and provider. Because those who perceive discrimination are less likely to regularly visit their doctor unless for emergency visits, they are also less likely to receive health screenings like mammography for Black women (Burns et al., 1996). Reasonably, perceiving the health care system as racist corresponds with disengagement from said system and ultimately negatively effects health outcomes for Black women. Albeit this goes beyond perceived discrimination; compared to white women, physicians are less likely to encourage Black women to have mammography, a blatant demonstration of medical racism against Black women (Burns et al., 1996). This speaks to the idea that perceived discrimination is often real discrimination and part of what occurs in a racist system is that Black women are not referred for screening *and* visit the doctor less because they recognize these types of discriminatory practices in their encounters.

Correspondingly, a theme that presents in the literature regarding perceived discrimination speaks to the question of “how do you know?” When individuals sense differential treatment, it is common to use “previous experiences as a gauge for determining the acceptability of such behaviour” (Ross et al., 2012, p. 533). It is difficult to authenticate discrimination, bias, and differential treatment, yet many describe a persistent feeling among Black women that something is amiss (Sacks, 2017; Anwar, 2019). Ross et al. (2012) describe participants who are convinced their experiences are differential to others because of their race, citing “intuitive ways of knowing” (p. 531). Many encounters that Black individuals recount are not stories of explicit racism, and yet there is a deep-seated feeling that discrimination has occurred. Examples of this ‘way of knowing’ are seen in participants’ descriptions of differences in quality and quantity of communication by medical staff, like being addressed by their first names after hearing staff call other patients by their last names. Cuevas, O’Brien & Saha (2016) and Ross et al. (2012) help to highlight what Black individuals view as discriminatory. For example, not being interacted with in the same ways as white female patients lead Black women to question whether they are being discriminated against, while a long time in the waiting room compared to other patients is seen as discriminatory for Black men (Cuevas, O’Brien & Saha, 2016; Ross et al., 2012). Often experiences of discrimination begin in the waiting room or front desk, where Black patients report feeling mistreated or differential treatment from medical staff (Cuevas O’Brien & Saha, 2016; Sacks, 2017; Ross et al., 2016).

As stated, this intuitive way of knowing comes from using previous experiences act as a reference point for understanding other discriminatory encounters. This is reinforced in a study of young Black women's perceived experiences of racial discrimination in health care encounters where adolescent women aged 13-21 years old infrequently perceived discrimination in reproductive health care (Lewis, Mollen, Forke, Peter, Pati & Medina, 2016). This suggests that adolescents do not recognize discrimination in the same ways as adults do, likely because of that experience factor. Though the girls did not perceive discrimination, they recount their health care providers making assumptions about their sexuality and sexual activity. As academics, we would establish these stereotypes as rooted in historical stereotypes and make ties to slavery where Black women were subjected to violence and unwanted sexual acts and how this is perpetuated in the stereotype that Black women are "naturally promiscuous" (Lewis et al., 2016, p. 5). Even without this historical knowledge, it can be said that adult women would recognize that these inferences around their sexuality are tied to racist structures. Despite not acknowledging these sexual assumptions made by providers as discrimination, discrimination was occurring. This study reveals that acts of discrimination can go undetected by those experiencing it. Thus, looking into Black girls and women's experiences under the guise of perceived discrimination may not be the best way to research challenging encounters they have in accessing care.

Beyond women's ways of knowing that racism exists and occurs within their interactions with health care providers, research has shown that experiences of racism result in particular consequences. Cuevas, O'Brien & Saha (2016) highlight three themes or barriers regarding the interactions between Black patients and their health care providers; these themes overlap in their effects. First, Black women report having to assert their interests constantly to receive adequate treatment. Second, mistrust of health care providers, either from experience of discrimination or learned from reference groups, is a persistent theme (Cuevas, O'Brien & Saha, 2016). For example, Black women who feel their doctors do not advocate for them are more likely to develop mistrust (Cuevas, O’Brien & Saha, 2016). Third, Black women express experiences of not being listened to, having their symptoms ignored or their comments devalued (Cuevas, O’Brien & Saha, 2016; Ross et al., 2016; Sacks, 2017, 2018). Perceived discrimination leads to poor patient-provider communication indicated by patients’ reluctance to share information and passivity in conversation and decision-making, which leads to lower quality care (Cuevas, O’Brien & Saha, 2016). This link between themes contributes to an “underuse of health care services and negative health care experiences” for Black women (Cuevas, O’Brien & Saha, 2016, p. 992).

Barrier to Care: Patient-Provider Relationship

Research on patient-provider relationships suggest how important this relationship is in determining quality of care and health outcomes. In an exploration of quality of care as it relates to the race and gender of both patient and provider, research finds that Black patients perceive their visits with providers as less participatory than white patients do unless their doctor is also Black (Cooper-Patrick, Gallo, Gonzales, Thi Vu, Powe, Nelson & Ford, 1999). More recently, Cuevas, O’Brien & Saha (2016) confirm that Black patients with Black clinicians rate their encounters as more collaborative than those with non-Black clinicians. Cooper-Patrick et al. (1999) contribute to a large body of research that indicates that partnership and communication between patients and clinicians are often influenced by ethnic and racial differences. It could be that being of the same ethnic, cultural or racial group means sharing beliefs, values, certain implied understandings, and experiences and so communicating and collaborating is made easier. The same is said for gender and the preference minority women have for seeing women physicians who they feel provide a level of gender sensitivity that they would not receive otherwise (Williams et al., 2011).

Barrier to Care: Lack of Cultural Awareness of Providers

Lack of cultural awareness of clinicians is another persistent barrier in the literature (Jones, Hopson, Warner, Hardiman & James, 2015; Williams et al., 2011). Interestingly, while participation and collaboration may increase when patients and doctors are of the same race, more recent studies reveal the reality that being treated by a physician of the same ethnic or cultural group does not always imply getting better quality care or an absence of stereotyping and discrimination (Sacks, 2018; Williams et al., 2011). Though multiple studies indicate participants believe having a clinician of the same race would facilitate better communication and compassion, the majority of participants of these studies also say they mostly want a doctor who demonstrates (cultural) competency – a tenet not necessarily linked to race, ethnicity and culture (Cuevas, O'Brien & Saha, 2016; Williams et al., 2011). Some Black women seeking mental health and substance abuse services report a preference for a clinician of the same race and gender, while others preferences are not specific to race or gender, but rather prioritize that they are listened to (Jones et al., 2015). Similarly, participants of Flynn & Taylor's (2009) study ask of their physicians to: be culturally sensitive and competent, be more sympathetic, be more thorough, ensure concerns are taken for what they are, not disregard or discount, be more helpful, be less sexist, and lastly, know more about Black women's health. Evidently, there is complexity in patient-doctor interactions where some Black patients perceive their interactions as better with a race-concordant doctor, while others do not, but in essence, Black individuals prefer and require good doctors.

Black Women's Experiences of Health Care

Racism is often seen as the primary oppression Black women encounter, which undermines the role of sexism and other oppressions in their experiences (Flynn & Taylor, 2009;

Sacks, 2018). For Black women, the intersection of race and gender is enough to activate discrimination. The challenge of receiving adequate health care is exaggerated when women are also experiencing barriers linked to homelessness, disability, sexuality, and HIV positive status, for example (Williams et al., 2011). Though analyses of these identities are out of the scope of this paper, it is worth noting that if Black middle-class women often avoid seeking health care leading to adverse health outcomes, this effect will disproportionately affect women who face the challenges that emerge from multiple identities (Sacks, 2017; Williams et al., 2011).

Black women's everyday access to general health care is missing from the current literature. Most research has been in specific areas of health to include mental health and maternal health. Research in those areas highlight the interplay of racism and sexism as barriers to specialized care that is consistent with barriers to primary care more broadly. A look to what the literature says about Black women's encounters in health care across a realm of health care sectors can be meaningful in understanding the perceptions of Black women as outlined above, especially considering the dearth of information about general health care.

Mental Health

Studies indicate that small percentages of Black women seek or receive decent mental health treatment compared to their white counterparts. Providers seem to detect depression in Black women less often and misdiagnose more; and so mistrust of the treatment system, combined with cultural insensitivity and fear of stigma often lead women to avoid use of professional services (Nelson, Shahid & Cardemil, 2020; Jones et al., 2015). Those who do have experiences in mental health and substance abuse services talk about experiences of grief and disappointment, being generalized as a Black woman part of the Black community, feeling their mental health concerns are evaded, or being alienated because of their addiction in conjunction with their race and gender (Nelson, Shahid & Cardemil, 2020; Jones et al., 2015).

Maternal Health

Villarosa (2018) explains that "the answer to the disparity in death rates" of Black mothers and babies "has everything to do with the lived experience of being a black woman in America" (p. 1). *Why America's Black Mothers and Babies Are in a Life-or-Death Crisis* outlines the birth experiences of a young mother of two who provides real accounts of her experiences in maternal health care in the United States (U.S). In Villarosa's (2018) research, the mother reports having her complaints of headaches, swelling, tiredness, aches dismissed by a doctor, consistent themes that align with other research of Black women's experiences in maternal care and health care more broadly. Black mothers report experience of waiting months before an initial prenatal appointment, being ignored, scolded, demeaned, feeling pressured into agreeing to C-sections (Villarosa, 2018). In general, the Centers for Disease Control and Prevention has declared that Black women in the U.S. are three to four times more likely to die in pregnancy-related causes than white women, which has caused an increase in the use of doulas, who act as advocates for Black mothers who are vulnerable in maternal health settings (Williams, 2018; Villarosa, 2018). Black maternity and racial disparity research is widely based on U.S. statistics, though research suggests Canadian Black women experience similar relatives disparities to American Black women, as seen in Canadian Black women having more preterm babies than Canadian white women, for example (McKinnon, Yang, Kramer, Bushnik, Sheppard & Kaufman, 2016).

Needs for Primary Care Information and Support / Community Based Responses

Where are Women Getting Support?

In light of Black women having challenging encounters in health care spaces, research suggests that women are looking for support in spaces where they feel safer and more comfortable, particularly with each other (Eng, 1993). In fact, reliance on social support proves as a central coping mechanism for Black women managing racist and sexist discrimination (Shorter-Gooden, 2004). A major theme in Eng's (1993) *Save Our Sisters Project* that seeks to develop a social network strategy for rural Black women, is that in matters of women's health, women pursue advice, help and support from other women, most often women they know (family, friends, and job networks being the main supports). Although Eng's project has aged, this idea that Black women, and other women of colour, turn to informal supports for assistance in health care remains today. In the *Every Woman Matters* report, half of the women participants report informal support networks, such as family and friends, as most helpful in accessing health care services. These include bringing family members to doctor's visits to act as advocates or hiring a doula to assist in the birthing process (Ross et al., 2012; Cuevas, O'Brien & Saha, 2016; Villarosa, 2018). In addition to family and friends, service providers outside of the health care system, such as social workers and clergy, are noted as valuable (Williams et al., 2011; Jones et al., 2015). Similarly, young Black women are highly influenced by family, friends and partners in getting health information and making decisions around health, specifically reproductive health (Laz & Berenson, 2012). Often Black women are depending on informal sources instead of health care professionals showcasing a lack of trust of professionals (Bailey, 2016; Cuevas, O'Brien & Saha, 2016; Laz & Berenson, 2012). The literature suggests that women find ways to be resourceful, while highlighting the difficulties women face in accessing services as they are needing to lean on personal relationships and community services for trusted support in navigating the health care system. Williams et al. (2011) refer to these as “extra-systemic health care facilitators” (p. 49).

Social Relationships and Peer Support

The importance of social relationships in the maintenance of health and well-being is well-documented. This literature, however, is generalized and not framed to address racial or gendered barriers in accessing peer support. In other words, peer support literature within the health care context is rarely Black woman specific. After breaking down the words ‘peer’ and ‘support’ and what they mean on their own, Dennis (2003) defines peer support as “the giving of assistance and encouragement by an individual considered equal” (p. 323). This definition accurately explains how peer support is defined in the context of this project. Social support, a “multidimensional construct” that usually involves the following dimensions: “informational, emotional, esteem, tangible and social network” is also meaningful (Hether, Murphy & Valente, 2014, p. 1426). It is known that people turn to those in their social network as a “‘first contact’ person when addressing health concerns prior to, or in lieu of seeking professional help and accessing the formal health-care system” – these are called “natural lay helpers” (Dennis, 2003, p. 328). The *Save Our Sisters Project* incorporates the use of natural lay helpers in reaching older Black women through their immediate social networks to influence breast cancer screening (Eng, 1993). Research points to “women-centered networks as instrumental in Black women’s day-to-day survival and as a vital element when faced with life’s stressors” (Norris & Mitchell, 2014, p. 7).

Online Platforms and Social Media

In recent times, peer support as been available online. In Ontario at this moment, there does not exist a support or advocacy platform that speaks to the everyday kind of concerns that would take Black women to their general practitioners, which establishes a need to dig deep into the needs and concerns of Black women to develop a platform to access peer support. Many health care platforms like Virtual Care Ontario provide virtual care solutions so individuals have access to care exist, however, on these types of platforms, the peer support piece that this project explores is missing (OTN, 2020b). Big White Wall is an example of an Ontario wide peer-to-peer support community for mental health, but the specificity to Black individuals or women is missing (OTN, 2020a).

Research suggests Black women want and need peer support, especially when managing experiences of racism and sexism (Eng, 1993; Shorter-Gooden, 2004; Norris & Mitchell, 2014). There is a question to be answered about the ways Black women can use online peer support platforms more practically. Mommy Monitor is an excellent example of an online Black maternal health platform designed to meet the needs of Black mothers. Through education, empowerment, acknowledgement of health inequity, and advancement of cultural competency, Mommy Monitor provides better solutions for moms and babies; this is done by giving women the opportunities to connect with Black maternal health professionals, mentor and be mentored by other mothers, join workshops and other events, and more (Mommy Monitor, 2017). Another question lies in whether these types of existing platforms are effective and the answer will remain unknown until research is done on the uptake and success of these platforms. However, the existence and use of Mommy Monitor indicates that online peer support is helpful for Black women. Extending peer support to a different, specifically designed online platform of more general health concerns where women can diversify the social networks they rely on for reliable and safe health information, advice, support and advocacy will be beneficial.

In conclusion, research demonstrates that Black women are getting support from other Black women (Eng, 1993), informal support networks like family, friends and other advocates (Ross et al., 2012; Cuevas, O'Brien & Saha, 2016; Villarosa, 2018), and service providers outside of health care (Williams et al., 2011; Jones et al., 2015). There is also an awareness that women-centered networks are invaluable for Black women's everyday coping with stressors, including health and well-being stressors (Norris & Mitchell, 2014). Online peer support is an important avenue for Black women and my research is concerned with how this can be further developed with the inclusion of Black women. This research seeks to fill a gap by highlighting what needs to be known to support the development of this online platform.

METHODOLOGY

Overview of Methodology

As part of conducting qualitative research, this project uses Black feminist methodology (BFM) as the way to operationalize Black feminist epistemologies. Black feminist methodology falls under critical social science (CSS) research which works to reveal myths and hidden truths, while working for, by and through people to help them change the world for themselves; CSS is action-oriented and empowering and makes attempts to confront injustice (Neuman, 1997).

Black feminist methodological practice incorporates three components. First, prioritizing the first-person narrative. Second, compensation of participants as way to demonstrate the Black feminist belief that all people are inherently valuable and worthy of respect and dignity (Moffett-Bateau, 2015); and third, involvement of the communities from which participants are living (Moffett-Bateau, 2015). This articulates that engagement with and learning about participants' community, such as asking participants how they feel about their experiences and asking about interpersonal relationships including interactions with family and friends. With this in mind, my research about health care experiences has to go beyond just that and look at where women are coming from and how they interact with the people around them, which corresponds greatly with the support and advocacy piece of my research question.

Methods

Participant Recruitment and Engagement

Through one 2-hour virtual focus group, this study centres the voices of six self-identified Black women. Inclusion criteria included self-identification as a Black woman, being a current student or alumnae of McMaster University and having personal experience in the Canadian medical care system. Age and class were not explicitly explored in the criteria for participation, as they were not part of the research question; however, all women were under 26 years old and it is assumed these women are middle-class given their attendance at a top tier Canadian university, and references to age and class are made in data collection and analysis to reflect this.

Recruitment was done entirely online. The recruitment poster (appendix 1) was initially shared on social media platforms, Instagram and Facebook, because of the presence of young, Black women who engage with these sites. Email recruitment scripts (appendix 2) were also sent to on-campus networks, such as the Graduate Student Association and the African Caribbean Graduate Students Association, to reach current Black students at McMaster. Instagram proved as an essential platform for sharing of the recruitment poster by Black women who were interested or had followers they thought may be interested. Through this, women emailed me detailing their interest and were then sent the Letter of Information (appendix 3) to read more about the study. Participants provided oral consent via telephone and an oral consent log (appendix 4) was completed and documented prior to the focus group. This process involved agreeing to be a participant, agreeing to be audio recorded for the purposes of transcription, and agreeing to be contacted about a follow up consultation, if necessary.

Data Collection: Focus Group with Black Women

The COVID-19 pandemic required alternatives to in-person data collection procedures. I conducted one virtual focus group via Zoom Video Communications (Zoom) in early May 2020. Six self-identified Black women who expressed interest and were available to fulfill involvement in the study participated. Participants were given $10 honoraria for participating, in honour of Black feminist methodologies tenet of compensation.

Focus groups are ‘focused’ in that they involve a collective activity (Kitzinger, 1994). In this case, Black women were encouraged to come together, talk about their health care encounters and what they would like to see in a health-related support platform to better meet their needs. Through collective “testimonies,” women and groups of women produce their own voices and visions, which can act as an empowering experience, especially for women of colour (Kamberelis & Dimitriadis, 2013). A focus group allows for interaction between participants, more concentration on other participants and for participants to determine the priorities of the research (Kitzinger, 1994).

I heavily relied on Collins’ (1986, 1989) work in data collection and analysis. I decided Black feminism and focus groups aligned well. As per Collins, there is a responsibility to “acknowledge the ways Black women have their own needs, concerns, and experiences, which need to be addressed in their specificity” (Kamberelis & Dimitriadis, 2013, p. 8). Kamberelis & Dimitriadis (2013), who rely greatly on the ideas of professor and diversity scholar, Esther Madriz, assert that focus groups can act as an important ingredient in the progression of social justice for women because, as a method, it “expose[s] and validate[s] women’s everyday experiences of subjugation and their individual and collective survival and resistance strategies”(p. 6). Embedded in the Black feminism methodological theory is a “first-person narrative,” where women of colour are given spaces and opportunities to tell their stories, providing data that is both accurate and meaningful and adds to a tradition of Black feminist thought (Moffett-Bateau, 2015, p. 55). By following the Black feminist methodological practice and its prioritization of first-person narratives, questions were asked in ways that allowed women to speak to their experiences, with limited probing by myself as the researcher. In analysis, I also wanted to continue to highlight this narrative.

Furthermore, while speaking to the importance of self-definition as a tenet of Black feminist thought, Collins (1986) highlights the work of other Black feminist scholars like that of Lena Wright Myers, who demonstrates that “Black women judge their behaviour by comparing themselves to Black women facing similar situations and thus demonstrates the presence of Black female definitions” of Black womanhood (p. 18). This idea of self-definition greatly influenced the decision to conduct a focus group method in that interpersonal relationships could be facilitated among Black women. Collins (1986) mentions the notion of sisterhood, “generally understood to mean a supportive feeling of loyalty and attachment to other women stemming from a shared feeling of oppression,” and how this has been an important part of Black women’s culture rarely explored elsewhere (p. 22). My hopes were for more than just the sharing of common oppressions; I wanted to emphasize community, and peer support and advocacy. How women consult with each other, while remaining autonomous in their understandings of their own experiences, was especially significant. For this reason, I decided against individual interviews as they would not have given this communal element. Individual interviews would have given women the opportunity to provide more in-depth accounts of their insights, understandings and experiences, while connecting with other Black women via focus group allows women to speak both collectively and individually, bringing to surface agreements and disagreements to be had as different articulations of similar experiences are shared (Kamberelis & Dimitriadis, 2013). This collective identity is especially significant in the co-development of a platform that will represent diverse groups of Black women. Choosing focus groups meant understanding the limitations and ethical challenges that focus groups pose. For one, dominant voices that may not represent individual views may emerge in focus groups (Sim & Waterfield, 2019). Related to this, equal participation is difficult to ensure. Health jargon was avoided in my questions and discussion so all participants, not just those with medical backgrounds, felt they could contribute comfortably. I hoped this would encourage equal participation. Participants were also reminded that all voices were to be heard, and were given the opportunity to add details after discussion had concluded.

Patterson et al. (2016) provide a guide of how to use Black feminist methodology in research in meaningful ways. I resonate with the elements that they present in their research, such as being Black women conducting research with Black participants and considering intersectional feminism in creating reasonable, open questions that allow women to create their own narrative. Among my first questions were “What are some of the experiences you’ve had *as a Black woman* accessing health care?” further prompted by “Have you had positive experiences accessing health care? What made them positive? Or have you had challenging experiences accessing health care? What made them challenging?” These questions were asked so that they were not leading and did not specifically point to racism or sexism, though I suspected these transgressions may be discussed. If women talked about positive experiences, those were received with the same energy and appreciation as when they spoke to challenging experiences. Other questions asked were:

1) What words come to mind when you think of the word “health?” This may include physical, mental, spiritual, sexual, or other types of health.
2) How did you manage these challenges?
3) Where do you receive support regarding (challenges in) accessing health care? Who do you talk to? Has anyone come to you for support?
4) Have you considered or used online/social media platforms as a resource to gain information about health and health care? Why or why not?

5) What would you like the focus of an online platform about Black female health to be?
6) Now imagine this ideal online platform! What does it look like?

Additionally, in an effort to operationalize the components of Black feminist methodologies in my research, I made attempts to tap into learning about where the women were from and where they seek health care-related help and support. I asked, “Where do you receive support regarding accessing health care?” to get a sense of what tools, strategies and people the women were already tapping into to have their needs met. In asking about the online platform, I asked “What would be helpful for you in an online platform geared towards Black women who are seeking health care related support?” to allow for varied answers and prioritization of issues based on what participants felt most important to them. This question in particular was asked to bring up different tangible suggestions that Black women want for health-related support as a way to mobilize the knowledge that women have.

Data Analysis and Interpretation

Black women have access to both the Afrocentric and the feminist standpoints, and so “an alternative epistemology used to rearticulate a Black women's standpoint reflects elements of both traditions” and should be mirrored in data analysis (Collins, 1989, p. 756). Paired with this, Collins (1989) suggests the significance of a Black feminist epistemology lies in its ability to advance our conceptualization of how subordinate groups create and disseminate knowledge to resist race and gender oppression. Methodologies that measure and assess marginalized populations are limited, and both in spite of this and as a response to this, Black feminist methodologies developed, pushing against traditional feminism’s erasure of communities of colour (Moffett-Bateau, 2015). For analysis, this indicates a commitment to uncovering underlying structures that oppress women of colour, but in a way where women talk about their own experiences.

Thematic Analysis

Thematic analysis is a popular method of qualitative data analysis that systemically identifies and organizes data into themes (Braun & Clarke, 2012). There is a focus on establishing patterns of meaning and shared experiences across the data set and then work is done to make sense of these trends (Braun & Clarke, 2012). Literal and interpretative readings of qualitative data can be done to organize the data set (Mason, 2002). I incorporated both these types of readings into my coding, and therefore, analysis. Literal readings assisted in understanding whether my questions were answered, the language and words were used by participants in their discussions and the interactions between participants. Interpretative readings helped decipher the women's interpretations of their experiences from my own interpretations of their accounts.

The idea of focusing on the young, Black, university educated woman's voice permeated my analysis of the data. Intersectionality and Black feminist thought as my theoretical frameworks acted as grounding forces from which to analyze the data. Because of this, the questions I asked of the data went beyond simply exploring challenges; analysis considered privileges, and oppressions, as a consequence of the Black woman identity. For example, in the focus group, I asked about positive experiences and what made them positive. This question sought to understand the dimensions of experiences of Black women, and I hoped to use this same agenda to analyze.

Once transcription of the focus group was complete, I did a literal read through the data to assess what was there. Then, I began a thematic grouping of concepts via Microsoft Word. I initially developed my analysis around two main questions: 1) The challenges women face because of their multiple identities in navigating primary care services; and 2) what the women wanted in an online health-related support platform. Reading through the transcript, I highlighted in two different colours the quotes that represented answers to these two questions. However, the first question proved to be complex. For example, women explained their challenges in navigating health care, but also the roles they feel they have to take on, and the strategies they have developed to have a more positive experience. I coded these as separate themes in separate colours. Following this sequence, I finished coding with thirteen themes; some of which were interrelated and could be explained under a single heading (race and gender concordance and familiarity as they relate to patient-provider interactions). In developing themes as related to the two research questions, I was then able to do a more interpretive reading of the data. “How are woman perceiving their own experience?” was a question I asked of the data that was especially helpful. Though I made interpretations, the women’s responses were quite clear in what they represented.

Secondly, what the women wanted mediated in the form of an online platform of support was analyzed. Black feminist thought is important here because of its emphasis on creating new knowledge and its interest in community. These components of Black feminist thought were helpful in reading the recommendations made by women of the group, to interpret why these were important to the women in the group and to endorse the creation of an online platform that they thought out in the meeting. A number of themes presented under recommendations, as they did for challenges. I coded these similarly, using different colours to identify the different themes in recommendations made by the women. I did an interpretative read of these themes to answer the question of why these recommendations were important, and because women had identified challenges they faced earlier, this task was more about linking themes and connecting statements.

Ethics

Ethics was approved by the McMaster University Research Ethics Board. One ethical concern that presented itself was the reality that participants may know each other, being Black women attending McMaster University, and be hesitant to speak of their experiences around their direct peers. To mediate this worry, the Letter of Information (appendix 3) outlined that participation via webcam was not mandatory and that names could be changed before and upon entering the Zoom meeting to maintain confidentiality.

Additionally, it can be argued that Black people fail to respond to research because it often reflects the interests of privileged groups in that the tools and language used are inaccessible to marginalized populations (Moffett-Bateau, 2015). Black researchers conducting research with Black participants does not automatically alleviate this inaccessibility; however, Black feminist methodology’s prioritization of first-person narratives where questions are open-ended to allow participants to develop their own narrative, limit the opportunity for participants to be confused or feel disconnected from the research questions. In my years at McMaster University, I was not made aware of research that pertained to how a phenomenon was experienced by Black women. I hoped to conduct a study that was accessible to Black women. I was also very transparent about this study being part of a requirement to obtain a master’s degree. Additionally, as a Black researcher, in highlighting the stories of these women, my own story is told. The inclusion criteria of this study is deeply reflective of my identities, and though the quotes below were not said by me, they very much represent thoughts or experiences I, too, have had. A challenge for me was understanding that research cannot be objective, but though I am connected to these stories, they are not mine, and I have the responsibility to share them in ways that are ethical and representative of the individuals who told them.

Reflexivity and Positionality

Tied to the Black women's standpoint, knowledge exists on two levels. The first level of knowledge that Collins (1989) speaks to is facilitated in the conversations women have with each other. The second level of knowledge is expedited in research. Through research, I hope to share the group's standpoint on the challenges of navigating health care as a young, Black woman, with the intention to create a platform that promotes what women require to overcome said challenges. Berger and Luckmann's approach to Black feminist thought acts a reclamation of what counts as knowledge (Collins, 1989). Me, a Black feminist researcher, doing work to conceptualize the health care experiences of other Black women, contributes to data about Black women, but in ways where Black women and positionality are at the center of analysis. Black feminist thought reinforces that Black women are carriers of knowledge and power that enables them to confront race, gender, and class oppression, and that it is beneficial to disseminate this new knowledge.

The identities attached to a young, Black educated woman carry privilege; privilege as an aspect of position is not often seen taken up in research about marginalized women. Focus on the intersections of race and gender is only a starting point for looking at other dimensions of identity that interact and shape how people experience the world. The violence Black women encounter is a consequence of a series of dimensions of their identities – race and gender only being two examples; this idea also points to the implications intersectionality as a theory has in addressing the issues and needs of Black women (Crenshaw, 1991). At the same time, intersectionality is significant because it allows us to consider privileges in conjunction with transgressions based on race and gender in analysis.

FINDINGS

Six self-identified Black women participated in this project. All the women completed their undergraduate degrees at McMaster University, and though they are Black alumnae of the same institution, the women come from different educational backgrounds, knowledges, ethnicities and experiences. Some of the women currently work in health care or have close family or friends working in health care, which drew out unique perspectives as an insider element was apparent in their discussions. In line with my theoretical frameworks, I had chosen to take a qualitative approach to attend to women's thoughts, reflections and recommendations, but also so women could hear what other women were contributing. Great discussion was generated this way. Women were very reflective, often reaching conclusions about their experiences on their own and explicitly introducing themes. Seven themes emerged from the analysis of the focus group to include: the acknowledgement of privilege, how the Black woman identity shows up in health care settings, the labour Black women engage in to receive health care, what women want in their health care interactions, accessing support, recommendations for an online platform, and lastly, peer support within the focus group.

1. Acknowledging the Privilege that Comes with Being a University Educated Black Woman

Many of the women came to the conclusion that being young, Black and university educated provided them with an advantage when navigating health care. As A.R. stated: "*We all have Canadian accents which helps us navigate health care a little differently than say, immigrants would.*"

This was followed up by M.O., who, in acknowledging her privilege, shared:

> *"I think honestly, for the most part, I've had positive interactions. Although looking back in hindsight they could have been better but they're still – I know that there are definitely worse interactions that have happened. I think definitely recognizing for myself that it's a privilege to be an educated Black woman, because the story shared about the language barrier, like I can't even comprehend that."*

More directly tied to the topic of navigating health care, S.K. articulated how she acknowledges that her privilege can aid her in health care interactions:

> *"I use my privilege in terms of my education to hit them that way in when I'm advocating for myself, as opposed to just out of raw emotion or frustration where, I don't know – that's why I just take that out of the equation … I'm not communicating with them that way where they just see me as an angry Black woman…"*

These examples demonstrate how the Black women who participated in the focus group were able to recognize their privilege in contrast to other Black women who, for example, are not Canadian-born and who may not hold the same level of higher education. They also recognized that these privileges assist in accessing health care. At the same time, acknowledging privilege does not erase the ways that racism permeates the health care experience for Black women, as seen in the next theme.

2. Being a Black Woman in Health Care Settings

Emerging from the focus group discussion were concerns about the ways that women experienced health care. One particular setting that came up early in the focus group was the walk-in clinic.

a. The experience of health care in walk-in clinics

A central theme emerging from the focus group discussion was that women shared experiences of being ignored or dismissed within the context of their health care experiences, particularly when attempting to access a walk-in clinic. When I asked the women to share any challenges they have experienced when attempting to access health care, M.O. recalls:

> *"Sometimes it kind of feels like if I'm not saying keywords, they're not taking me seriously. So it's like, am I just someone else on the schedule? Like are you going to sit down and listen to me? 'cause I just waited here for however long to see you..."*

T.M. adds:

> *"When I go to a walk-in doctor or something, maybe I can't see my family doctor right away, I don't know if its because of the nature of a walk-in clinic where they just want to see you and pass you along quick[ly], but I find that they don't really look into what you're saying. Like [participant] was saying, they don't really believe you at first … I feel like they're really quick to pass you off … I went to a walk-in clinic just 'cause I wanted like a quick solution and the walk-in doctor, who was a woman, she tried to just be like 'Oh yeah, you have pre-diabetes,' like that's it."*

The use of the phrase "pass you off" suggests that women feel rushed or hurried out of their health care encounters. In addition, being passed off was also equated to not being believed that they had a legitimate health concern. Participants shared that the walk-in clinic experience has taught them what they needed to do in order to get their health care needs met in the future. As M.O. echoes:

> "*I was like I'm going back to my family doctor, I'm not doing this anymore where people can just pass me through the system so if I do have to go to the walk in, it's literally I have all my symptoms laid out, I've already Googled a couple options … Just going for medicine."*

The idea of being "passed through" or "passed along" resurfaces in the women's stories. Many women speak of accessing walk-in clinics as a last resort and not wanting to return after low quality interactions in this setting. Many participants spoke to the underlying frustration that exists for Black women when accessing walk-in clinic services – this idea that they are just bodies, undeserving of attention and care. The women shared experiences of being in walk-in spaces and feeling a lack of concern about their health issue, either demonstrated by walk-in providers downplaying concerns, not looking into concerns thoroughly or simply not believing them. Consequently, the delegitimization of concerns in the context of walk-in health care spaces leads women to develop skills that would support them in getting their health care needs met. Although the women did not speak to whether or not they thought that these experiences were a consequence of their identities as Black women, they did discuss the impact these experiences have on the way they navigate health care settings more generally, in relation to being a Black woman.

b. Racism and identity

Some participants were explicit about how the Black woman identity shows up in their experiences in health care settings and how they understand being a Black woman as different from the identities of the health care providers and staff they interact with. K.M. explains:

> *"I think I'm just really conscious, if anything, that I'm a Black woman especially when I'm stepping into these places where the entire health care setting – the doctor, the receptionist – are all going to be white. It's not that it takes away from the experience at all, but it just makes me more conscious that like this who I am, and hopefully they don't treat me differently because of it."*

Noticing all the people with power in the room are white incites a fear that anti-Black racism will enter the interaction, impacting the ways she accesses health care. This is really important because as she says, it is not that it takes away from the experience of receiving health care, but it impacts her experience of accessing health care because of what she knows and has experienced in regards to racism. These perceptions by Black women are largely made as a result of knowing how Black individuals are treated in health settings. This theme is established further in the ways women recognize and then manage racism in health care encounters. As S.K. says:

> *"I know that there's a phenomenon they talk about with Black people being perceived stronger than they actually are in terms of pain. So when you're describing your symptoms, a lot of times, they're easy to write it off because they don't think that we are experiencing something to the severity that we're describing it as. So I think that that's where I think about myself as a Black woman, and that's why I kind of - I think that's where I had to learn to use the right words to describe what I'm feeling."*

Despite having and acknowledging that they possess privileges as university-educated Black women, racism inherently impacts the women's experiences within health care settings. The women had compelling conversations where they made analyses of themselves and their experiences based in their Black woman identity. Understanding anti-Black racism and misogynoir as active in health care implicates the ways in which women understand their own identity and show up in health care spaces. For one, participants recount a hyper-awareness or consciousness that their identities as Black women may make for differential treatment or other difficult experiences, as shown by participants hoping they are not treated unfairly because they are Black. This awareness is also shown in women being intentional about what they articulate to providers. The women's experiences highlight key sentiments about the treatment of Black women by health care providers and underscore the intersection of racism and sexism Black women face.

3. The Labour of Black Women in Health Care

It was important for me to identify positive, as well as challenging experiences to tell an inclusive story about Black women's navigation of health care. It became evident very early in the focus group that the women put in extra work that they feel ensures more positive interactions with health care providers. The previous themes and the ones to come inherently represent a form of labour that Black women engage in to navigate health care spaces and receive adequate care. More specifically, self advocating, preparing, researching, and performing for interactions with providers are other examples of the strategies Black women have developed to combat racism, sexism or a combination of both in health care spaces.

a. Black women's role of self-advocator

In response to confronting the intersection of racism and sexism within health care settings, the women highlighted the need to engage in self advocacy efforts that would potentially result in better access to care, and better treatment while in care. S.K. provides insight about the act of self-advocacy:

> *"It kind of sucks, but I think that it would really have to start with us, that when we go into appointments, we take the time to sort of check, like check them seriously, like saying 'that is not okay.' It can be a lot of emotional labour, but it's either we wait until they all retire, they make education mandatory, or we speak up for ourselves."*

Here, S.K. suggests Black women stand up for themselves by explicitly naming things providers do as unacceptable. She points to the need to engage in self advocacy while acknowledging its emotional toll. The labour Black women put into receiving adequate health care is undesirable and taxing and can take a lot out of women to do. Another participant describes the many layers that go into advocating for themself; A.R. says:

> *"We can be passive in those situations because like [participant] said you come out and you're like 'is it because I'm Black that they did that?' and you're not having that dialogue with them. And I think it can be intimidating too, to be like, 'well, why aren't you going to do that for me?' or whatever, so I think in that case it's our job to advocate for ourselves in those ways."*

This participant suggests Black women have more dialogue with their health care providers, asking questions about why providers make the decisions they make. Hence, self-advocating is seen as a necessary step in receiving proper treatment and managing a systemically racism health care system. Though their advocacy may look different, the women showed an awareness about the necessity to speak up and campaign for their needs in health care settings that they experience as racist and sexist, and therefore threatening to Black women. Either discrimination and bias are occurring in women's experiences or they understand discrimination and bias as possibilities in their encounters and advocate for themselves as to establish a safeguard against this discrimination. Knowing that they cannot expect discrimination and bias to simply disappear as it is systemically embedded into the threads of the health care system, women see this work as an alternative to waiting for the health care system to change.

b. Preparing

Women spoke to feeling the need to prepare for interactions with health care providers either in preparing themselves for the questions they may be asked or preparing the questions they must ask. M.O. recounts her frustration in preparing:

> *"And learning in that sense that like I need to figure out for myself what's going on so I turn to like taking health into my own hands and researching and trying to figure out ahead of time to prepare myself for the questions that the doctor is going to ask me, although sometimes it kind of feels like if I'm not saying keywords, they're not taking me seriously."*

K.M. echoes this sentiment by saying:

> *"I think I definitely feel the whole aspect when they say you've got to work twice as hard. That's how I feel when it comes to health care and being a Black woman. I just feel like due to me taking my health seriously … if I'm going to the doctors or the hospital or whatever it may be I'm on my Ps and Qs. I have to know my questions, I have to do a bit of research before going there, have an understanding of what it is. I can't just go there and say 'okay this is what I'm feeling' and expect to get the best results out of my health care because I know that Black women aren't adequately treated in health care already so it's my due diligence to, you know, be a bit more proactive and be more involved and aware of my health prior to getting involved in the health care system."*

Undoubtedly, this summarizes the thoughts of the group. Perceptions of not being taken seriously intermingle with this relentless theme of having to prepare. Preparation acts as a form of advocacy that seeks to legitimize women's concerns; they are preparing as a safeguard to be taken more seriously. Considering this, preparation gives Black women power back into their encounters with health care providers. Knowing they are saying the right words, knowing they have questions to ask and answers to potential questions are only some examples of preparing that have worked for the women in getting their health care needs met. While empowering, this also reinforces an unaltered system of inequality that expects women to find strategies to mitigate disparities and discrimination, which is unfair to Black women and is the reason I have called this phenomenon 'labour.'

c. Researching

Another consistent strategy that women expressed engaging in when preparing for a medical appointment was to do their own research on their health issue or concern prior to. For example, S.K. revealed:

> *"I started doing research on the condition I had and when I do go into those specialist appointments … they see you more as an intellectual when you can use the terms that they're using and things like that. And it actually helped with my appointments going forward*."

Whether it assists in counteracting racism or sexism, having to do research prior to an appointment to have the provider take one more seriously is labour. Additionally, this idea that having medical terminology on hand aids in communication and therefore enhances the provision of the doctor's appointment is a chore. "*They see you more as an intellectual*" stands out because it reveals a perceived judgment by the participant about how doctors see her in their appointments, based on her experience. T.M. also asserted that research is important:

> *"…so when you go to the doctor, you can kind of listen to them, but also if you're hearing what they're saying isn't what you believe to be true for yourself and what you're feeling in your own body, you can kind of be like no, maybe let's check this again. So it's kind of just being more educated on stuff. Like I've been to the doctor before where, again, they just kind of push me off and I'm like 'no no no there's actually something going on, it could be this." And they're like 'oh yeah, let's do tests."*

Here, though in agreement with the previous participant, T.M. demonstrates another point – that research acts as a form of advocacy, but also as protection for Black women in encounters with health care providers. Research is used to support what women say and feel. On the other hand, M.O. expressed regret about not doing research prior to a specialist appointment:

> *"He recommended that I go get a cardiogram or an echocardiogram or something. And I didn't prepare for that one either but walking out of there I was like I definitely need to do my research next time I'm going for a procedure. I didn't know I had to [laughs] show my chest and all this, to a man."*

M.O., like many women in the focus group, usually do research before appointments. Having not done research this time, she felt unprepared for what the procedure entailed. Her regret speaks to the importance Black women place on preparation. Having not done research before this appointment proved a mistake as she was not equipped with the knowledge she needed to endure what became an uncomfortable encounter. Research as labour but also protection demonstrates it as a type of 'necessary evil.'

d. Performing

Participants disentangle the concept of preparing from how they perform. Women spoke to using their education and using medical terminology in medical encounters to appear more "*intellectual*." S.K. spoke to being conscious of how she presents herself as not to perpetuate the stereotypes she perceives providers have of Black women:

> *"I guess the other thing is just like when I am speaking up, knowing that they have this sassy Black woman or angry Black woman narrative, so being mindful of the language that I use. So that's like why I use my privilege in terms of my education to hit them that way in terms of when I'm advocating for myself, as opposed to just out of raw emotion or frustration - so that's why I just take that out of the equation in terms of like, I make sure that I know so I'm not communicating with them that way where they just see me as an angry Black woman who doesn't really know what's wrong with her, and they don't have time to deal with that."*

A.R. agreed, following up with:

> "*You have to kind of change your tone, change your language and that's something that I completely understand."*

These thoughts about communicating in ways that do not give into negative stereotypes are significant because they highlight what women are doing in response to anti-Black racism in health care. Tone policing, for example, is a response to understanding stereotyping and therefore discrimination occurs in health care spaces for Black women. Though this speaks to the labour women engage in to get treatment, it also speaks to the awareness the women in the focus group had regarding the circumstances that affect Black women in health care and how these are maintained by racism. Women understand the struggle to defend their bodies and being, another unfair task.

4. What Black Women Want in their Health Care Experiences

From both their positive and challenging experiences, women indicated the qualities they want established in their relationships with health care providers. These appear in three sub-themes: wanting a provider who they are familiar with, wanting a provider who reflects their identities, and wanting a provider who is culturally sensitive and caring.

a. Familiarity in the patient-provider relationship

An important theme emerging from the women's discussion were the ways that the patient-provider interaction could be enhanced. One key finding was the value of having a long-term, trusting relationship with a physician. As T.M. shared:

> *"Yeah, I find that I get better, I guess, standards of practice when I go to somebody who I know, or somebody I have a connection with, rather than somebody that I don't."*

Echoing this statement, S.K. shared:

> *"Also familiarity, so like my gynecologist and general doctor was my mom's doctor. So, when she took me on, being familiar with my mom and then having my mom kind of transfer me to her, she, sort of, advocate[d] for me when I first transitioned. And then her being able to grow up with me, through my adult life, that really helped, in terms of positive [experiences]."*

Women perceived their experiences to be more secure when interacting with physicians they are familiar with. In fact, familiarity was a key ingredient to a trusting patient-provider health care experience. As M.O. shared:

> "*I think the theme of familiarity is something that, like resonates strongly with me. Just because of like, I've had the same family doctor since like I came to Canada when I was*

> *like 2 or 3. And he's in Brampton and we've moved and gone to Mississauga, and I would still drive back to my doctor because he's never led me astray."*

The women came to the theme of familiarity while discussing their positive experiences. Unsurprisingly, there is a level of comfort and safety women feel when they visit a physician they have been going to regularly or a physician referred to them by someone they trust. This helps us understand further why walk-in clinic experiences are especially challenging, because that familiarity piece that makes for a more positive experience is missing.

b. Shared identities

Another interesting theme that emerged was the value of having a shared identity or experience with one's health care provider. Commonality seems to build a connection or relationship that flourishes and creates positive experiences for Black women. D.D. explains:

> *"I do have the habit of going to walk-in doctors or such, and when I did finally find a doctor, it was through a walk-in clinic and she was sweet and I actually liked her a lot. She was Asian, which was really different, and she went to McMaster, so that's where the familiarity came in and I was able to really connect on that level."*

In D.D.'s case, graduating from the same school initiated a trusting relationship. Additionally, in looking at the language she uses, it was important for her to state that the doctor was not Black, which shows that race concordance is not the exclusive factor in a positive patient-provider relationship and also demystifies the idea that Black people only feel comfortable with Black doctors; they simply want a doctor that can relate to them in ways that strengthen the relationship.

As told by the participants, a challenging aspect of navigating health care for them was managing interactions with male physicians who did little to relate to the women or make them feel comfortable. For example, some of the women identified having negative experiences with male physicians. S.K. explained:

> *"…with my interactions with, for example, males, which a lot of times were negative initially because I feel like they either don't believe what you're saying or they don't break things down to you in a way that you can understand. Like sometimes they feel like it's a waste of time to even explain the terms that they're saying."*

This participant describes the ways she felt belittled in her interactions with male physicians, an experience she explains was not a single occurrence. Sexism is at the center of this experience, highlighted in the perception that men providers "feel like it's a waste of time to even explain." This was echoed by M.O., who shared a different challenge with a male physician:

> "*I didn't know that I had to [laughs] show my chest and all this, to a man, who was using that little monitor thing. It was very uncomfortable; he didn't do anything to make me feel comfortable so I just wish there were more females in health care that I would feel comfortable with."*

Interestingly, without being explicitly asked to, the participants assert the characteristics of a doctor that they would feel comfortable with and that would therefore improve their experiences. This included minority and Black female physicians:

> *"My positive experiences were made when my – the person that was providing care to me was a woman … Especially minority females."*

Some participants believed that encounters with Black woman physicians specifically would be even more positive:

> *"If the health care practitioner is a Black woman, that would just make me feel, or hopefully it would make me feel more heard, more seen, more understood and things like that, you know. Just the approach that I feel a Black practitioner would have, I think it would just create a different experience for sure."*

The majority of participants say they feel, or imagine they would feel, especially satisfied in their encounters with a Black female practitioner, as further shown in A.R.'s experience:

> *"I want to speak to positive experiences. For the last four years I've had a Black female doctor and it's just too easy, like I feel really lucky … I walk in there and she's like 'okay we're doing a full check up' … If I have a stomach ache, she's like 'okay, let's check it out, go for an ultrasound, go right now if you can' and she'll call them because I live in Hamilton and she's in Brampton and she knows I only come down when I can … I can see her advocating for me which is a really different experience."*

c. Reform

Women also spoke to what they want changed in medical systems they interact with, which included a need for more culturally sensitive and caring providers. These were recognized as things outside of the women's control and emerged from challenges they explained they experience. While talking about what needs to change in health care, S.K. says:

> *"I think that re-educating or making [re-education] mandatory… I know in the hospital they have a lot of courses and things like that, but they're not mandatory. A lot of the time nurses and doctors don't make time for these things so they're not things they value. Like how to talk to people, how to understand and integrate cultural competency into their [delivery of] care. So I think mandatory education."*

In line with cultural competency, K.M. suggests:

> *"I think they [health care providers] can just have a more caring approach, you know. Like when I'm dealing with my health, I want to feel like you really genuinely care about what I'm going through. Don't just treat me like a patient or somebody who's just in and out the door, like I know that that's their reality, but like for me, it's my entire health. So I want them to be more – especially as a Black woman too, when I obviously question and think like 'is this a race thing, is this a me thing?' Like you know, so it's like just be – have a more humanistic approach, be a bit more caring."*

Understanding that certain aspects of the patient-provider interaction are out of their control likely leads Black women to remain visiting providers they are familiar with. This gives women control in situations where they may feel powerless. Hence, there is a level of trust that exists in the patient-provider relationship when the patient knows the provider or feels a sense of commonality. This may relate to the theme of familiarity – having commonalities with a person usually makes for better relationships; the patient-provider relationship is no different. Additionally, the intersection of the Black and woman identities are a unique experience and one that can be explained easier when the individual you are connecting with knows what it is you are feeling and understands the language you are using. It can be said that tone policing would be less of an issue for a Black woman with a Black woman physician. A.R.'s example also shows there is a different level of advocacy when the physician is a Black woman compared to physicians who are men. A.R. adds: *"I know that not all Black women are lucky enough to have a Black female doctor that they know will advocate for them*" as to indicate an awareness that she is privileged in her situation. In a lighthearted response, M.O. says to A.R. that she "*found a unicorn*" in finding "*a Black female doctor*" in the city she lives in.

5. Accessing Health Care Support Beyond the Health Care System

Support outside the health care system emerged as a critical finding that was manifested in three different yet connected ways. The first was in regard to the ways women find health care support through family and friends, and the second was in regard to the ways the women access support online. Support manifests in different ways in the discussion: some look for help accessing services or health advice, while others find it helpful to read accounts from individuals with a similar condition. These various types of assistance are characterized as support.

a. Support from family and friends

The participants expressed the ways they receive help from friends and family members and how this makes for positive experiences:

> *"Generally all of my health care experiences have been pretty good, but I think that has to do with the fact that my mom's a nurse so most of the time, she's the one who books, if it's a specialized appointment that I need like she's the one who books it for me. And like she'll know the doctor who is going to see me or she knows somebody who knows the doctor so generally, I guess, they're more receptive."*

Many participants had instances where they rely on family with connections in health care to assist in their access and navigation of health care. Though some participants are in a sort of privileged position where they have these advantages, this also speaks to the understanding of racism and sexism at play in health care and capitalizing on opportunities that make these less able to permeate their experience. Women also identified relying on friends, but for support, comfort, and encouragement:

> *"I typically talk to my friends. I share my experiences with them, I receive their feedback, if they have answers or anything useful for me to do with that information then I make do of that. But there's definitely a group of people I rely on, especially when it comes to things like health care … sometimes it just something I want to confide more in with my friends, you know so they're definitely a big support system and that's who I go to."*

Friends proved as an integral support system in navigating and understanding health matters. Others explained the matters they go to their friends for: "*It's really convenient to go to friends for support. Sexual health especially is something I would go to my friends for support in, and not my family,"* while some justify why friends are their first option in making sense of health concerns:

> "*I find that I go to my friends first if its [a] subject that I don't feel comfortable going to my parents about for my health … so I feel like I go to my friend's first and if they're like 'yeah, go to a doctor' then I refer to my family doctor."*

Comfortability and commonality come back into play when looking at who and where women go to receive different levels of support. This need for outside support from family and friends is very telling of the operations of health care settings and its implications for Black women in care. There is a lack of support in health care for Black women where they feel better supported by outside resources.

b. Experiences of online support

Women also look to virtual resources for various types of support. A topic that came up in the focus group was accessing health information. A variety of social media sites (Twitter, Instagram, Snapchat, and Facebook) proved to be main sources women use to access health information and advice in preparation for navigating health appointments. Though social media and online platforms are used by participants to access health information, the ways in which these sites are utilized differ. While some use them to simply read information, some use them to understand other individuals' experiences with a similar condition or issue or to feel supported in their own issue. K.M. illustrates:

> *"When it comes to resources, I do like Google, but I like hearing human experiences in regard to whatever my questions are, so I don't go on WebMD or any of those websites. I'm more the type to be on a forum or on Reddit … I like to hear the different experiences that people had with whatever situation I'm looking at, whether they're positive, negative, whatever it may be. I just like reading it because that makes me understand … I'm not the type to actually write and leave comments and stuff, but I'm definitely an avid reader. Shout out to the people that post, but I'm not really the type to leave something, but it feels like support, like you know, like reading what they're saying, it feels like enough support that I need at the time."*

Simply being a reader of virtual posts corresponds with receiving necessary support. It was important to have women illustrate their thoughts around online platforms and social media in accessing and navigating health to comprehend where they are coming from in their recommendations for an online platform for health-related support and advocacy. According to participants like D.D.:

> "*I think definitely a support group in general is very necessary and would be amazing for Black women especially navigating the health system. I just think about those Facebook groups"*.

The women's knowledge of what already exists helped to fuel their suggestions for the development of our own support platform in meaningful ways. They made it clear that although virtual platforms already exist where women access information and support, one that is critical of how other platforms operate and dedicated to Black women specifically would be purposeful and significant.

6. Recommendations & Suggestions for an Online Platform

Correspondingly, a final yet imperative finding from the focus group was the recommendations that the women shared in developing an online peer support health care platform for Black women. In the focus group, explicit questions around the focus of an online platform and what would be helpful for Black women were asked to elicit recommendations for building said platform. The women's previously shared experiences, both positive and challenging, and the use of other online platforms, gave meaning to their suggestions. As for what should be included in the online platform, the women were in agreement about what was important for a platform to be useful for Black women. Their visions for a platform include it: a) being moderated by experienced Black woman health professionals, b) including peer-reviewed articles, c) having a community component, d) including information that pertains to the Black family, e) and advocacy, and lastly, f) it being both a website and an application (app).

a. A regulated platform led by health professionals

Though the idea of the platform, from my original perspective, was meant to be rooted in support and advocacy for navigating health care, the women made it clear that access to health information was also important for them. However, the conversation began with some weariness about using the Internet for searching health information and advice. In addressing this hesitancy, ideas about who should be moderating the platform was a central conversation:

> *"I think, say if we did a forum, or like an official forum, if it were to be led by say 2 official doctors, or a doctor or a therapist or whatever, and then people ask their questions below – as long as they're sifting through it and making sure nothing crazy is going on, I think that would be a forum I would definitely join, and take seriously rather than just a Facebook comment or a WebMD comment or something like that."*

K.M. adds that the racial and gender identities of the moderators is important in building a safe and secure platform for Black women:

> "*I think the idea that [participant] suggested earlier where it's something like a Facebook group or forum but it's led by 2 doctors or whatever – having an actual knowledgeable person leading it, that person obviously being a Black woman, I think that would be a cool platform idea."*

The women were unapologetically expressive about their visions for the set up of the platform that would best serve their needs. After first contributing stories about male health care providers who did little to provide a comfortable space or demonstrate acknowledgement of their feelings, concerns and voices, and then recalling positive experiences with women providers, participants had a strong sense of who they wanted in a space meant to recognize their struggles and issues.

b. Importance of scholarly articles

In sharing visions for the online platform, women discussed the significance of access to reliable information, hence the requirement of the platform being moderated by knowledgeable Black woman professionals. This is followed up by the idea of including peer-reviewed scholarly articles of different topics on the platform, so women have access to dependable educational tools at their fingertips. S.K. summarizes the ideas of the group:

> *"Everybody kind of hit the nail on the head in terms of what I would want in a platform … I definitely think it'd be moderated by a health care professional who can sort of censor things that are not sound health care advice that anybody should be having. I think that I'd also – having threads would be good. [And] an area where you can find only scholarly information … And combining [participant's] ideas as well, making sure you have peer-reviewed articles as well. I think that's a really good piece to add in for people who aren't okay with just reading the comments, just having those 2 options."*

M.O. adds to the importance of having scholarly articles:

> *"I think it's important to have the option for people to read further with the scholarly articles so that they can kind of take their health into their own hands, instead of just having a doctor on there telling them what they need, they can do the research for themselves, discern for themselves."*

While moderators are seen as a significant need for the platform, participants also added that displaying scholarly articles allows women to be autonomous in their health journey, not unconditionally relying on the advice or information given by the moderators. The alumnae identity of the women shows up in their recommendations; it can be said that university educated women prioritize scholarly information because of their educational background.

c. Community

Women outlined going to social media and online platforms for support and community; a lot of their experiences are demonstrated in their visions for a platform. M.O. states:

> *"I think we all kind of agreed that a forum or some sort of chat would be definitely unique because it's missing, I think, a bit in our society so I think that would be definitely a need for our app."*

This community aspect becomes more solidified later in the focus group with suggestions about how this community condition can be operationalized:

> *"I don't think there would be anything wrong with having an all-encompassing platform that has options for a community section where there's replying and there is a doctor that's part of that conversation. Or you can use the app specifically to just search things and have peer reviewed articles - come up … But a place that has all the information accessible and then from there whether you are actually specifically looking for a specific need like a maternal group, or you're going through a health concern, then either having like a forum that comes off of the app onto a separate platform or Facebook group that is secure to that specific need, 'cause then that's how you build community, right?"*

Earlier, K.M. spoke to reviewing stories made by other people online and not necessarily engaging with them, but nonetheless finding these helpful in understanding her own concerns or experiences. This community aspect is significant because it allows those who want to engage to do so, but also for observers to still benefit from reading information, tips, strategies, and issues posed by others. Women would have the autonomy to engage at their comfortable level. I believe the community forum on the platform could expedite what was facilitated in the focus group in terms of how the women interacted.

d. Acknowledging the dynamics of the Black family

Navigating health within the Black family was an important theme that came up in recommendations for a support platform. Participants agreed that managing how to bring up health related issues in a Black family is a *"a very important topic to be discussed."* In thinking about how to operationalize this complicated topic, S.K. advised:

> *"Having a section on the online platform with different videos that you could watch with whoever it is in your family that you're trying to [speak to about a certain topic] … And then generate the dialogue that way, I think that'd be a good way to use the platform to sort of do that."*

In acknowledging issues specific to Black bodies and families, D.D. mentions:

> *"If you were to have the family aspect of it like to include all the symptoms or issues that affect the Black family most and Black women most … maybe that would peak their interest a little bit more. And then, like everyone was saying, making a video or something that would gather their attention and create an opportunity for conversation where it's not too hostile between the parents or the child or whoever the conversation is being had between; so they don't feel like they're being belittled or told they're not doing something right."*

In the group, women agree that having information to share with family instead of taking on the work of explaining would be helpful. A.R. proposed:

> *"I think having a platform that maybe just like puts out information like "hey, there's a panel about health" and you making the decision to bring your family or not is something that you can do, but you have the information just there and you can make that decision. I think, too, like a lot of events happen in the black community and we don't necessarily know about them, educational platforms or panels, so I think that too is something I think about when I'm thinking about a platform for Black women and health. Just like an events table where people are privy to information that they wouldn't necessarily be privy to without this thing."*

The idea of bringing family to events extended to other support people also:

> *"I really like that idea in terms of the events tab. I feel like a lot of our generation, we go to workshops or panels and stuff like that and we complain but then we don't really bring in like our parents or our family or those that are sort of the source of our grief or issues with us to receive that education, so I think that's really good. An events tab would be great."*

Related to this, some participants were explicit about what they would not go to their family to seek support with. A.R. states:

> *I think sexual health especially is something that I would go to my friends for support in, not family… I think there are certain sectors of health that I would go to people my age for. We talk more about physical health, we talk about spiritual health, we talk about sexual and mental health.*

There was an unspoken, shared understanding around the obstacle that is initiating difficult conversations around topics like sexual and mental health in Black families. The women's suggestions are rooted in experience and desire to make other women's experiences more positive. Their ideas communicate a type of support and advocacy where Black women acknowledge the issues they face and work to alleviate these issues for their peers.

e. Advocacy of Black women on the platform

You will recall that self-advocacy is a theme the women expressed in understanding the dimensions of their identities and the experiences they have as a result – a theme that directly corresponds with the vision for advocacy to be employed on the platform. Women reveal creative suggestions for advocacy to be operationalized:

> *"And so that's something too, like how to advocate for yourself would be something that would be cool to add to a platform. If people are looking to access services that they've never accessed before or get help in kind of navigating a tricky or racist doctor that they kind of just have to see. That's something that I would add just based on what you guys were talking about."*

S.K. adds:

> *"I think, too, to add to the platform: one, knowing your rights, like your patient rights within Canada… And then not only knowing your rights but then the second: knowing when you do have those instances with that doctor ... how to report that 'cause there's ways to report that… But if those instances never get reported that's why they're still allowed to practice and do this to other patients, so I think those would also be two very important things to have in there as well. And knowing what their responsibility is, so your rights and their responsibilities, so they can't just shoo you away, they can't do certain things. When you know like okay this guy is actually not doing what he supposed to do, it's not a race thing, he's literally just negligent at this point. And reviews! Maybe doctor reviews would be another thing to add in there."*

Some participants were privy to this type of information and felt that all Black women should have this knowledge as a way to improve their experiences if racism, sexism and negligence continue to live in Black women's encounters. These visions demonstrate an unwritten sisterhood where Black women look out for others in informing them of strategies that enhance their well-being. This idea of sisterhood is maintained in M.O.'s suggestion:

> "*I definitely feel like there is a need for recommendations, even as we grow older and may want to switch family doctors or whatever. A forum where you can recommend a doctor."*

Additionally, participants ideas around advocacy are seen in aiding other Black women in finding providers that have been exemplar in their practice by promoting them publicly. This would also work to keep providers accountable for their actions, another method of self- and peer-advocacy. Evidently, there is an issue of access to health care for Black women as a response to anti-Black racism and misogynoir that has been demonstrated throughout the focus group and especially in these quotes. Women had previously expressed different ideas of what advocacy meant to them; for some, this meant speaking up in encounters, for others this meant asking direct questions about whether providers actions (being dismissive) are linked to patient identity (being a Black woman). Importantly, women began thinking past their own experiences of advocacy into how the platform can be used by other Black women to aid in the difficulty of accessing services. Advocacy shows up in different ways for the women, though they illustrate the same theme in ensuring the platform includes ways for Black women to know their rights, report negligent providers, and hold providers accountable for their actions.

f. Organization of the platform

Lastly, the women and I discussed their visions for the set up of the platform. How the platform should be organized is of value because it leans into giving women the opportunity to emphasize what is symbolic for them. M.O. stated:

> *"I would say maybe both [an app and a website.] Like you would have a desktop version and then also an app that you can use on the go, and I guess that's sort of similar to the Facebook forums online where you can do it on your desktop or your mobile phone. Just so you can reach people where they are."*

This idea of having accessible information at your fingertips very much speaks to the ease and appeal that social media has today and a health-related support platform should be no different. In deliberating about what is valuable, a discussion in the focus group focused on the target audience. D.D. stated an important point about how age should be considered in the development of the platform:

> "*I think for youth an app would be beneficial. I'm just thinking of my mom and older people who – like she just actually is really beginning to understand her phone. So if she were to be on it, I'd be having to assist her to gain understanding, but definitely an online forum of some sort would be ideal."*

Participants identify ways in which the platform can be used to appeal to different populations. This is interesting because inclusion criteria for the project included current students or recent graduates of McMaster University, and yet women were thinking about how their friends and family may use the platform they build; the women's perceptions of the platform extend beyond the women in the meeting to the women they interact with daily. This is significant in designing a platform that is specific to the needs of Black women and can be employed by a number of different Black women regardless of age, ability, sex or other identity categories. D.D. then spokes to the notion of a comprehensive design:

> *"Ideally, I would hope to have it be all-encompassing; as long as there is a tab for each subject like I'm definitely going to go through all of them. Definitely something for mental health, I think that's definitely underrated in the Black community, and then well-being, which could also include physical health. And then sexual health is very important*

> *as well. I would make those three categories the top to start. I think those categories are important because they're so underrated. Those are things that we're well affected by as a whole, in our community, and not just based on regional things, but just us being Black … Also I think a lot of our generation is misinformed or underinformed about certain topics about sexual health, well-being and physical health and how that all relates."*

The women were clear about why certain categories are meaningful for them. Specific topics of health being underrated and undervalued in the Black community is expressed in this sentiment. The idea of not being focused on one particular topic, but also being specialized complicates the conclusion to have an all-encompassing platform and therefore presents some considerations for how the platform is organized. K.M., who both agrees and disagrees with the majority of the group, shares her thoughts:

> *"I think a platform where the different subjects are separated is cool. I think it could be overwhelming having everything accessible. I mean it's definitely cool accessibility wise when everything's just there but I feel like if I'm a teen mom, I want to be on a teen mom platform, period … So I think I'd be comfortable with something catered solely to multiple things, but like each of them having its own platform."*

What this participant outlines is that the platform can exist in both an specific and ambiguous space, an idea that needs to be fleshed out more deeply with the women again in subsequent meetings if granted the opportunity to build said platform. I highlight this specific difference because it speaks to a need for more Black-specific health initiatives that concentrate on undervalued populations. The women's suggestions very much address their identities. The platform being moderated by health professionals addresses the alumnae identity, while the community recommendations lends to the sisterhood that exists between Black women. The platform has grown from an idea about health-related support to one that incorporates the different strategies and suggestions of a group of women who also see it important to have access to health information that makes their everyday health encounters more positive. There is much value in listening to Black women and their visions for issues that concern them.

7. Peer Support Within the Focus Group

A product of the focus group methodology was a reciprocal exchange of information and support beyond the women's immediate networks of friends/family or their favourite social media/online platforms. It is important to include how peer support worked in action in the context of the focus group as I witnessed peer support and advocacy among the participants in their discussions. While talking about recommendations for an online platform, M.O. backs the idea of a forum and emphasizes a forum should be a place:

> *"…where you have a bunch of people and then you're actually personal with them, 'cause like right now I'm learning a lot. I'm taking notes about telehealth and a bunch of things. I'm grateful for this opportunity right now. So like building off of that, I think would be a unique opportunity."*

She explains the opportunity to engage in a focus group about health is a 'unique opportunity' which points to a need for more conversations and events for women to connect, feel heard, and share, the objectives of what our proposed online platform seeks to facilitate. Women were transparent about their feelings about being part of a group and sharing knowledge. The focus group proved to ignite relationships – participants recognize similarities between each other, asking questions like: "*Did that work? Because I have eczema too."*

Some women exhibit thoughts of regret in not taking an action they now feel they should have taken after hearing the stories of other women:

> *"Definitely hearing these conversations today and then having that conversation with my chiropractor makes me think about how I definitely do need to find a doctor, and also one that will advocate for me and the needs that I have, or any needs I need to figure out."*

Hearing women's stories of advocacy helped to ignite a sense of confidence and inspire others to think about advocating for themselves differently. There also developed a sense of belonging; this most resonated with me as the facilitator when M.O. made a recommendation for the online platform and ended her thought with: *"…so I think that would definitely be a need for our app."* Use of the word "our" made it obvious for me that participants were perceiving themselves as part of a working group creating something for women like them. Similarly, the focus group ended with the following statements that speak to the journey the women went through together in the two-hour virtual meeting:

D.D: *This was sweet. You guys were so nice. I'm gunna take your tips.*

M.O.: *I learned so much on this call.*

S.K.: *This is great, guys. [Participant], feel free to hit me up.*

Two members of the group had made a connection as one had identified herself as a resource and another in need of a family doctor. They verbally agreed to allow me to share their information so they could talk further after the focus group. Furthermore, women were calling each other by their names and affirming what they had learned from each other, underscoring the importance of safer spaces where peer support and community building can occur.

These findings outline the ways women perceive their health care experiences. Based on these experiences, the women share what is most important for them to be taken up in an online health-related support platform focused on Black women. Through discussion in the virtual focus group, women tapped into the resources and networks they use regularly to undertake the task that is navigating health care. I believe the focus group did this and more as women were able to receive feedback from each other about their strategies and thoughts around a platform that would be beneficial for all Black women in Ontario. The suggestions segment of the findings is especially significant for me to highlight in my research because it is rooted in Black women's struggles, wisdom and partnership, all of which should be recognized and implemented in an authentic, working social platform. There is no better way to understand what Black women need than to ask them and involve them in the application of their solution.

DISCUSSION

The aim of this study was to gain insight into the experiences of Black women in health care and to build a participatory tool that can be employed to support other Black women in their health care navigation. The findings contribute to conceptualizing both the ways that participants perceive themselves as Black women accessing health care systems and for the development and implementation of an online support platform that reflect their needs and experiences. In this discussion, I highlight three particular themes that were most salient in the focus group. These include: learning that class privilege does not protect Black women's health; the labour that Black women engage in in order to access health care; and health care support and advocacy for Black women. In addition, the women shared important insights into how an online health platform developed by Black women for Black women would result in one valuable approach to addressing their health care education and support needs. These themes are important for making the point that there is room to talk about how Black women confront barriers to accessing health care and that we can value the intellectual tools of Black women in creating solutions that work for us.

Privilege Does Not Protect Black Women's Health

Although the women who participated in this study outwardly acknowledged their class and education privileges, this did not protect them from bumping up against anti-Black racism and sexism when accessing health care. Contrary to most existing research about Black women's access and navigation of health care that focuses primarily on particularly marginalized Black women, this research demonstrates that experiences of being ignored, dismissed, not believed, and therefore delegitimized, are issues for all Black women. My research echoes Sacks' (2019) who posits that "being a racial minority is usually equated with being poor, and so it's assumed that Black middle-class women should be fine because they're not poor. But they're not fine. They face substantial health challenges and differences in health outcomes" (Anwar, 2019). We need to acknowledge this side of the story where all Black women are marginalized in the health care system as long as it continues to operate in anti-Blackness.

There are several arguments for why class privilege does not protect Black women from being marginalized in health care settings. First, inequities in health and health care transcend class, insurance status and education, illustrating the implications of the interaction of race and gender and the very small role class plays when the Black and woman identity are combined (Sacks, 2017; Ross et al., 2012; Villarosa, 2018). The lack of research on middle-class Black women speaks to the tendency to understand race, gender and class as separate (Crenshaw, 1989). Additionally, Farmer & Ferraro's 2005 'diminishing returns hypothesis' posits that Black individuals receive declining health returns as socio-economic status (SES) increases, and that more education leads to more opportunities for Black individuals to be discriminated against (Sacks, 2017, 2018; Ross et al., 2012). Hence, an increase in SES does not equate to greater protection in health care settings. An example of this can be seen in the United States where educated Black women face higher rates of infant mortality than lesser educated white women (Anwar, 2019; Villarosa, 2018). More recently, the media is documenting Black maternal mortality and more research demonstrates "what Black women have always known: we can't buy our way of out dying in childbirth" (Crear-Perry, 2018).

This finding exposes a need for research to focus more on how race and racism affects minorities who are not poor, therefore broadening the understanding of the intersections of identities (Sacks 2017; 2018). The violence Black women experience is often a determinant of a series of identities and bias, discrimination, stereotypes and stigma of Black women in health care are deeply rooted in this intersection of gender and race (Crenshaw, 1991). This does not account for the impact of other systems of oppression: poverty, mental health, homophobia, and transphobia are other intersections that complicate the experience of health care access and exacerbate the substandard treatment of Black women (Williams et al., 2011). To overlook the ways these identities complicate Black women's circumstances is to disregard the other violent experiences they encounter based on other oppressions (Crenshaw, 1991). This reminds us that focus on the intersections of race and gender should only be a starting point for looking at other dimensions of identity that shape how Black women experience health and health care. Bias, discrimination, stereotyping and stigma ultimately have implications that live outside of the health care encounter, putting Black women and their health at risk. For example, Black women confront inequities in screening, diagnosis, and treatment, in part, because experiences of anti-Blackness impact their willingness to seek medical services (Burns et al., 1996; Sacks, 2013). This furthers substantiates the argument that class privilege cannot buy health for Black women. Though this is notable, it is not unexpected. Black women's intersectional experiences and the "unique compoundedness" of their identity have long been explained by Black feminists (Collins, 1989, p. 150). Without intersectionality, untrue conclusions about middle-class Black women may be made that would contradict this reality that class does not protect from experiencing anti-Black racism and sexism.

The Labour of Accessing Health Care

The women in this study work hard at getting their health care needs met. This is not surprising as Black women often engage in emotional and mental labour in order to get their needs met (Sacks, 2017; 2018). Echoing Sacks (2018), the women in the focus group demonstrate how educated Black middle-class women anticipate that they will confront discrimination in their encounters with health providers, which results in the labour of fighting for legitimacy. Thus, strategies for accessing health care are born. In *Invisible Visits: Black Middle-Class Women in the American Healthcare System,* Sacks (2018) explores the stories of middle-class Black women who experience race and gender discrimination in health care settings, and argues that going to the doctor as a Black woman requires “forethought, strategy, and great effort” (p. 1). In the focus group, the women’s acknowledgement that their experiences of health care could have been better, coupled with their perceived need to fight against stereotypes of Black women as “angry” when acting in frustration or dissatisfaction are only some examples of this forethought, strategy and effort. Even though the women maintain degrees of privilege, they still feel the need to arm themselves against stereotypes and their experiences of racism in health care settings. The work that the women do to navigate and attempt to access good health care includes self advocacy and an intricate combination of research, preparation and performance.

a) Self- advocacy as a Form of Labour

As documented in the literature, women of colour expect that they will encounter racism, stigma and other types of social exclusion in their health care encounters (Williams et al., 2011; Sacks, 2018). The identity categories attached to being a Black woman mean being hyperaware of the challenges you may encounter in your daily life. Tied to acknowledging potential struggles at the intersection of identity is this idea of self-advocacy. Reflected in the women’s focus group discussion was the need to self advocate, including feeling the need to speak up and question decisions when providers are providing less than desirable solutions or none at all. Research that acknowledges Black women’s challenges in accessing health care recognizes this labour. It is an “ongoing struggle to assert one’s humanity in the face of persistent race, gender, and class stereotypes" (Sacks, 2017, p. 10). Women in the focus group affirm this point by indicating this feeling that they are just bodies and not people deserving of attention and care.

Interestingly, health organizations encourage Black patients to advocate for themselves by asking questions, speaking up, asking for second opinions, and trusting their instincts (Wilson, 2019). This suggestion seems to almost defend anti-Black racism by putting the onus on the patient to do the work instead of looking at the system to change. It also neglects to recognize how self-advocacy from a Black patient can be looked at differently than advocacy by others; it may be looked at as hostility, or reinforce the negative stereotypes Black women spoke about in the focus group (for example, being the 'angry Black woman') (Wilson, 2019). There exists a double bind where substandard care means wanted to self-advocate, but self-advocating may mean receiving substandard care if it is seen as aggressive, hostile, or angry. Women realizing they should have advocated for themselves more in certain situations, like one with a male physician, are representations of this double bind.

b) Research, Preparation & Performance as Labour

Research and preparation before health care interactions and the subsequent performance that Black women engage in during appointments with physicians are largely explained by the reality that Black women's experiences in the health care system are riddled with negative stereotypes about their race and gender (Sacks, 2017). Sacks (2017) argues Black middle-class women are aware of the existence of stereotypes and use this knowledge in their interactions as a way to self-define, challenge stereotypical images and mediate potential bias, stereotyping and discrimination (Collins, 1986). This means being hyperaware of the way they dress, speak and even walk as a way to avoid being stereotyped; as we saw in the focus group; women understood that changing their tone parallels not perpetuating the 'angry Black woman' stereotype. The literature also draws attention to other caricatures, such as the “welfare queen,” that are narrow and unfair, and yet permeate Black women’s experiences in health care navigation and help clarify why Black women would do extra work to challenge these negative descriptions and interpretations of Black womanhood, lending into Collins (1986) notion of self-definition (Sacks, 2017, p. 2). By actively rejecting and resisting assumptions made about them by providers, Black women are able to cope with the oppression they experience (Collins, 1986).

The labour women in the focus group recall doing can be explained by Shim’s (2010) conceptualization of cultural health capital (CHC), a “collection of cultural skills, attitudes, behaviours and interactional styles” exchanged by both patient and provider during interactions (Sacks, 2017, p. 2). Cultural health capital, also called “self-presentation strategies,” include types of dress, verbal skills, educational credentials, and scientific or medical knowledge and lay in a person’s ability to communicate their social privilege and resources (Sacks, 2017; 2018). For successful health encounters, patients must be able to demonstrate that they are educated, have knowledge of medical topics and terminology and have the ability to communicate health information effectively and rationally, in addition to physical appearance and dress (Sacks, 2017). Women also recall having their symptoms laid out, googling and assigning symptoms to possible illnesses and preparing answers for questions physicians may ask them, all representations of CHC at play.

The patient-provider relationship is also driven by cultural health capital (Sacks, 2017; 2018). The literature maintains that patient perceptions of quality of care influence the patient-provider relationship. In most studies, including *Building a Network*, race concordance is less of a factor than simply having a ‘good’ doctor, and good quality of care is found to start with a trusting relationship (Dale, Polivka, Chaudry & Simmonds, 2010). Participants in the focus group talked about familiarity and commonalities as important for initiating this trusting relationship with providers. Black women developing a relationship with their provider is named important in “establishing themselves as rights-bearing health care citizens” (Sacks, 2017, p. 6). One way to do this is through the CHC domain of communicating articulately with the provider. A Black women’s ability to do this can be seen as resistance to stereotyping. In addition, the CHC tenet of communicating rationally directly corresponds with a participant’s sentiment that she does not advocate for herself out of ‘raw emotion or frustration,’ but uses her education to guide her language. Though helpful, this is problematic – Black women should not have to be equipped with medical knowledge, nor should they have to conceal their frustration to be treated equitably. This theme of performance is embedded in the focus group discussion as women consistently speak to using their education to counteract stereotypes by using medical terminology and knowing what terms to use to be taken seriously, other representations of CHC.

Ultimately, findings from the focus group parallel Sacks’ (2018) research where Black women emphasize their educational backgrounds or their ability to research medical issues but are still met with discrimination by providers. Though the expectation that Black women demonstrate CHC skills is arguable, there is also evidence that Black women emphasizing CHC skills works as a method of self-advocacy. This project’s findings illuminate Black women’s persistent efforts to resist discrimination and receive adequate health care in medical settings. All participants brought forth some struggle of being stereotyped in their encounters and using specific strategies of altering their behaviour or language to lessen potential discrimination. Evidently, there is a need to decrease the labour Black women engage in to access health care. This suggests that one potential way to address this labour is by developing an online support platform that includes the women’s visions for virtual peer support and advocacy.

The Vision: Virtual Peer Support and Advocacy

A critical observation that I witnessed in the focus group was the way the participants demonstrated mutual support in regard to their shared experiences of racism and sexism in health care contexts and a desire for virtual Black and women centered peer support and advocacy. Black-centered virtual support networks positively influence women and the networks they interact with. #Blackwomantwitter proved influential for Yamani Yansà Hernandez, who created the tweet that inspired this thesis, and the individuals who interacted with the tweet. Similarly, the women in the focus group have been positively influenced by the support and information they provided to each other. Both the thread under Yamani's tweet and the responses around participation in the focus group by participants display a need for more women-centered spaces where support operates. Collins (1986) often mentions a notion of sisterhood being build in a supportive feeling of attachment to other women rooted in shared oppressions. It is not to be said that all Black women automatically get along because they share experiences of oppression that come with being Black and a woman, but as seen in the focus group, there are unspoken understandings that Black women share that make support and building solutions more accessible.

In connecting to Norris & Mitchell's (2014) assertion that women-centred networks are central to Black women's survival, Hether, Murphy & Valente (2014) report that more women than men use social networking sites to search for health information online. Hence, it is not surprising that the women made suggestions for a virtual platform that is rooted in support or sisterhood where women recognize what they want for themselves and how this may apply for other Black women. Women undoubtedly embodied Dennis' (2003) definition of peer support by providing both assistance and encouragement during the focus group. In collaborating to create a virtual social platform for Black women, the participants created a virtual social network of their own.

As discussed, Black women want and need a platform rooted in support and advocacy for their health concerns (Donelle & Hoffman-Goetz, 2008). North Americans use the Internet to publicly access health care and medical information, formerly exclusive knowledge to health experts and providers (Donelle & Hoffman-Goetz, 2008). Online groups or chat rooms now act as significant virtual safe spaces for marginalized groups who are potentially seeking alternatives to accessing in-person health information, advice and support; ideas of online platforms in the literature point to a virtual space where information is accessible and sharing of similar experiences occurs, which sets up social support and a membership identity into a virtual community (Donelle & Hoffman-Goetz, 2008).

Novel interventions are needed to evaluate the development of culturally sensitive online resources for minority groups that showcase health information that aligns with their values, practices, and beliefs (Laz & Berenson, 2012). The development of new social support technologies that offer permanent and consistent resources for Black women have long been recommended (Bishop, Mehra, Bazzell & Smith, 2003; Norris & Mitchell, 2014). Chatrooms are one way Black women have offered their own experiences as examples of healing, and to encourage others, take on a collective identity, offer support through discussion, develop strategies in problem solving, set goals with each other, share articles, challenge readers to think about economics behind health care industries, and participate in political advocacy (Donelle & Hoffman-Goetz, 2008). An online health-related support platform would work to change the ways women communicate and collaborate (Bishop et al., 2003). Additionally, some women in the focus group expressed their varying comfortability in engaging in online platforms. Even those they call online “lurkers,” who simply observe posted information without actually engaging, benefit by having opportunities to improve their health via the health promotion that occurs in health care-related online platforms (Donelle & Hoffman-Goetz, 2008).

Although the women in the focus group spoke to various aspects of the broader health care system they would like to see changed (i.e. more Black woman representation in professional health care roles, cultural sensitivity in providers), there were many indications that women tap into other resources to manage the navigation of health care. Besides an overhaul of the system and who and what they already access, the women indicated that an online peer support platform would be beneficial for them if it included their recommendations. The literature that speaks to Black women supporting each other or finding outside support beyond the health care system is undeniable. Given the digital age, a virtual platform is a valuable resource that Black women can use to share health-related information and support each other in ways that relate to health care. As women identified the importance of a platform, they articulated what that platform should look like. It is important to note this is only one way that Black women can have their health care needs met and engage with other Black women around this topic, evidently because this is the question that was asked of the women in the focus group.

Suggestions for platform by the participants are rooted in experience, but also in knowledge about what is needed for Black women. Increasingly, individuals are turning to online platforms for health information and advice and there is a demand for online communication with health care providers (Nobles, Leas, Dredze & Ayers, 2020). The women’s suggestions for the platform to be mediated by a health professional and include scholarly information speak to the necessity of health literacy, defined as the social and cognitive skills that control an individual’s ability to access, comprehend and utilize information to promote good health. Nutbeam (2000) argues that by enhancing Black women's access to "health information and their capacity to use it effectively, health literacy is critical to empowerment" (as cited in Donelle & Hoffman-Goetz, 2008, p. 72). Health literacy enables people to ask necessary questions, report medical history, gain problem solving skills related to their health care, all forms of advocacy that the women in the focus group discussed. In the findings, key suggestions for the platform that link to health literacy are seen in featuring ways to advocate for yourself, know your patient rights, understand provider responsibilities, and review and recommend doctors. Women expressed these as important for themselves and for other Black women to learn in their own health journeys. These suggestions that promote health literacy are concrete examples of how the women seek peer advocacy and are dedicated to supporting each other.

Implications for Social Work in Health Care

Cultural competency and primary health care seem to be linked in both theory and practice, but in the last six years, there has been a switch from cultural competency to structural competency to be implemented in the training of medical systems (Oelke, Thurston & Arthur, 2013; Hansen, Braslow, Rohrbaugh, 2018; Metzl, Maybank & De Maio, 2020). Structural competency is a framework for acknowledging and addressing social justice issues that relate to health and systematically trains health care professionals to recognize ways that "institutions, neighborhood conditions, market forces, public policies, and health care delivery systems shape symptoms and diseases," to address health inequities (Metzl & Petty; 2017; Metzl, Maybank & De Maio, 2020, p. 231). Currently, there appears to be a focus on structural competency training as the antidote for anti-Black racism in health care (Oelke, Thurston & Arthur, 2013; Crear-Perry, Maybank, Keeys, Mitchell & Godbolt, 2020; Metzl, Maybank & De Maio, 2020). The ongoing switch from cultural competency to structural competency is a necessary one, as cultural competency only focused on physician bias and improving patient-provider communication and therefore fell short of "systemic intervention" and could not have been the standard for health care education and training (Metzl & Petty, 2017; Hansen, Braslow & Rohrbaugh, 2018, p. E2). What remains crucial is a structural shift in the health care system, one that involves a multitude of solutions rather than looking at medical training as the sole prescription for structural racism in medicine. Recently, in recognition of anti-racism protests across the world, health organizations have denounced anti-Black racism and declared "Black Lives Matter" (Crear-Perry et al., 2020). Declaration of this movement will be the true test of anti-Black racism in medicine. In honour of structural competency, there are a number of steps for medicine to become anti-racist: for one building an anti-racist, structural competency skills set among pre-medicine, pre-nursing and pre-social work students is a necessity, as is continuing education and anti-racist competency training throughout medical and social work careers, as a way of achieving "medical education justice" (Metzl & Petty, 2017; Crear-Perry et al., 2020, p. 453). This type of reform aligns with Collins (1990) assertion that social change comes from a changed consciousness of people and the transformation of institutions, and that these are not isolated events that can happen without the other. Black feminist thought also posits that historical understandings of Black folk assist in changing the circumstances of Black individuals today (Collins, 1990).

The system itself requires a full reset that addresses the history of Black individuals in health care and the continued failure to meet their needs today. Academics call for practical steps to incorporating an anti-racist lens to medicine in order to move toward health equity and structural justice. These steps include testing new innovations and algorithms in settings that serve populations that are not young, white, healthy patients, and rather diverse populations, like young, middle-class Black women, and diversifying health and social care providers (Crear-Perry et al., 2020). Additionally, changes to health care must consider and address the legacy of structural anti-Black racism in health care (Crear-Perry et al., 2020). For instance, the issue of mistrust of medical professionals that much of the Black community carries will ultimately affect the ways Black men and women seek and participate in health care.

Some research suggests Black women are a difficult population to reach for health care institutions (Bishop et al., 2003). Outside of structural competency and in action, social work can operate to provide connections between Black women and community health organizations, institutions, and partners for collaboration and development of tools and resources that will be helpful for Black women in their efforts to access and navigate health care. Connecting Black women to organizations like Women's Health in Women's Hands (WHIWH), a Toronto community health centre that specializes in service provision for racialized women, would be a straightforward task in assisting Black women and connecting them to more social support systems and ensuring their needs are met (Women's Health in Women's Hands, 2020). Based on their research, Norris & Mitchell (2014) suggest more formalized social support systems that offer permanent and consistent resources for Black women. This would allow for Black women to benefit from social support in a way that extends beyond their immediate social circles. Community organizing where Black women are introduced, connected, and bonded is one place to start. Furthermore, social work has to find its place in health, advocacy and media to push and support a paradigm shift where conscious raising and anti-racism is the standard in medicine (Crear-Perry, 2018). Social work also has a place in being vocal about how health disparities are inextricably linked to racism and advocate for Black women through organizations (like WHIWH), community initiatives and research.

In research, social work may address the lack of focus on certain populations of Black women. This may look like focusing more on diverse populations within the Black community as not to perpetuate the assumption that only individuals at the lowest ends of the financial and social spectrums face challenges as they relate to health care access. A big takeaway from this study is that more projects, interventions, and efforts of change for Black women must include Black women as to account more fully for the consequences that they face. Positioning Black women's experiences at the center of analysis offers fresh insights on … prevailing concepts, paradigms, and epistemologies" and this starts with working *with* Black women (Crenshaw, 1990, p. 553). Social workers who double as researchers and have a stake in the lives of Black women can launch action research projects that support the aims of Black women and incorporate Black women's subjective views. These views become specialized knowledge and inform ways to achieve practical social outcomes (Collins, 1989; Bishop et al., 2003). This process would reinforce that Black women carry knowledge and power that enables them to confront race, gender and class oppression (Crenshaw, 1990). Furthermore, Black women working with Black women to create new knowledge advances the production of Black feminist thought.

Norris & Mitchell (2014) also suggest for community-based health centres to be involved in the development of formalized social support programs that relate to health, as they have a better understanding of the needs, issues and priorities of the community (Norris & Mitchell, 2014). In Ontario, community health centres like TAIBU and WHIWH are integral in providing comprehensive primary health care to the Black community in the Greater Toronto Area and would be important to include in building any type of response to health inequity (TAIBU, 2020; Women's Health in Women's Hands, 2020). Both in and outside of research, social workers should look to Black women scholars, like Tina K. Sacks, and Black woman physicians, like Joia Crear-Perry, and ordinary Black woman, like those featured in this project, for information and feedback as to make decisions that are representative of such a diverse population of women.

The varying oppressions Black women face are often seen as barriers as opposed to the power that systems hold over marginalized persons as the barrier. I hope this misguided idea that identities are barriers is invalidated in this project. In the medical system, it is racism, not race, that is the driver of health inequities and substandard treatment of minority populations (Crear-Perry et al., 2020). Being Black is not the risk factor or the barrier, but exposure to anti-Black racism is (Crear-Perry, 2018). Likewise, sex and gender are not barriers, but patriarchy, white supremacy, heterosexism, homophobia and transphobia are the invisible risk factors that affect those living in certain identities. Likewise, structural competency is not the lone solution, but that and eliminating the barriers that make being a Black woman in health care settings difficult are. Black women should not have to rise above being Black and being a woman; they should be able to sit comfortably in the many identities they occupy and receive standard care without doing extra work to ensure this. There is a necessary dismantling of systems and demanding of accountability from folks who maintain and benefit from anti-Black racism and sexism in systems like health care. For now, our proposed online health-support platform is the quick fix. Though some work around the design of the platform need to be resolved, the foundation is honourable and reflective of the women that participated in this project, and therefore a powerful solution to barriers faced by Black women, regardless of class and education.

Limitations

Intersectionality is complex; individuals that fit into the Black woman identity encompass so much more than just the intersections of race, gender and class that are looked at in this paper, and those identities and positions need to be taken into consideration when exploring their experiences in health settings also. Methodologically, embedding intersectionality into the recruitment process will be important for subsequent focus groups. This will expand the groups of Black women involved in creating an online platform that is representative of more identities and social positions. This research project is limited in that it includes a small sample of similarly positioned women. This study does not look into the disparities or implications of Black women receiving substandard care and rather acknowledges that this reality exists and promotes an idea that allows Black women to be apart of their solution for accessing health care. The consequences for Black health and well-being ought to be investigated in other ways to find systematic solutions for anti-Black racism and gendered racism in health care. Additionally, it should be stated that the development of said online platform is only *one* way to acknowledge Black women's experiences and advance health and support. There are so many other ways Black women uptake sisterhood, community and peer-support. More research needs to be done to address the limitations and concerns of online health-related platforms to better attend to the weariness women expressed around using online health communication platforms. Lastly, participatory action research was meant to be used as a guiding methodology for this project, but because of the COVID-19 pandemic that made in-person gathering more difficult, those principles were evaded and a more traditional research lens was applied to the project. Although women made suggestions and recommendations for what should be included in the platform, it is wished that women could have been engaged in more participatory ways to make the online platform more authentic.

Conclusion

Overall, this study's findings on Black women's experiences in health care have been used to garner a collection of recommendations that can be implemented into a virtual support platform designed for and by Black women. Black women in the sample acknowledge the advantage they have in navigating health care as young, university-educated women with knowledge and capacities that not all have. There are many implications for further research to look deeper into the experiences of the largely skimmed over population of Black women who are middle-class and/or university-educated and yet encounter discrimination and bias in a Canadian context. Further research may also look at how other identity categories added to the Black woman identity complicate health care encounters and what these consequences mean for an inclusive, virtual support tool. The findings declare the huge role of intersectionality in Black women's lives and how the words and thoughts of traditional Black feminist scholars continue to reign in explaining the experiences of modern Black women. For the purposes of this thesis and as a method of dissemination, I have developed an online platform informed by the findings. This prototype of the online platform is available to view in the appendix (appendix 6).

"Health is a right and anti-racism is its right-bearer" (Crear-Perry et al., 2020, p. 453).

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APPENDIX 1:

RECRUITMENT POSTER

BLACK WOMEN'S VISIONS FOR PEER-ADVOCACY AND SUPPORT IN HEALTH CARE

McMaster University

Participants needed:

Are you a Black woman-identifying student, alum, faculty or staff?

Have thoughts about what you would need in an online platform regarding Black female health?

Please consider participating in a study about experiences in Canadian health care settings.

You will be asked to participate in a 2 hour online focus group. You will receive a $10 Visa Gift card for participation!

Please contact Ranece Gordon at gordonra@mcmaster.ca for details!

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance

APPENDIX 2:

EMAIL RECRUITMENT SCRIPT

E-mail Subject line: McMaster Study – Black Women's Visions for Health Care

Hi (name),

I am emailing to invite you to an online focus group part of a graduate research study I am working on regarding Black women's visions for online advocacy and support in health care. The purpose of the study is to explore Black women's interactions with health care services and providers, with the intention to demonstrate what Black women would need in an online platform that responds to their needs, issues and knowledge around navigating access to appropriate health care. Your participation would involve taking part in a 2-hour online focus group via Zoom Video Communications (Zoom) and will have the option of participating by audio or video. You would be joined by other students, alumni, faculty and staff of McMaster University and asked questions about your experiences in health care settings as a self-identified Black woman. The hope is that you experience the focus group as more than a participant, and rather a member of a group that shares their strengths and knowledge in meaningful ways.

Research findings will be used to illustrate the implications of an online healthcare-related platform that would be helpful in navigating health care spaces with other Black women. The research process aims to broaden the network of Black women part of the broad McMaster community to each other, work to alter and contribute to an ongoing conversation about Black health advancement.

The focus group will be online via Zoom. By using Zoom, you are able to choose a username that you are comfortable using in a group and participate in the meeting from anywhere. The meeting will be audio recorded and transcribed. With this comes the social risks of being identifiable by peers, and through your stories. Additionally, participants will be asked not to share what is discussed in the focus group; however, confidentiality cannot be guaranteed. Additionally, you may feel emotional discomfort or distress when expressing or listening to other's experiences in health care settings. Every effort will be taken to minimize these social and psychological risks, but you should be aware and consider said risks involved in the study.

Participation in the focus group is completely voluntary. You can stop being in this study at any time during the focus group. I have attached a copy of a letter of information about the study that gives you more detailed information about the study.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you any have concerns or questions about your rights as a participant or about the way the study is being conducted, you can contact:

The McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administration, Development and Support (ROADS)
E-mail: ethicsoffice@mcmaster.ca

If you feel this study is one that may be of interest to you, please let me know via email! Any questions or concerns can be discussed here or in another way that suits you. The date and time of the online focus group will soon be determined.

Thank you for your interest and consideration in taking part in this study!

Ranece Gordon-Folkes, BSW
Masters Candidate in Social Work
School of Social Work
McMaster University, Hamilton Ontario
gordonra@mcmaster.ca

APPENDIX 3:

Information Letter and Informed Consent Form

Focus Group Discussion

A Study of/about Black Women's Visions for Peer-Advocacy and Support in Health Care

Student Researcher:	**Faculty Supervisor:**
Ranece Gordon-Folkes	Dr. Saara Greene
School of Social Work	School of Social Work
McMaster University	McMaster University
Hamilton, Ontario, Canada	Hamilton, Ontario, Canada
E-mail: gordonra@mcmaster.ca	(905) 525-9140 ext. 23782
	E-mail: greenes@mcmaster.ca

Purpose of the Study

The purpose of this project is to explore Black women's interactions with health care services to demonstrate how Black women would use online platforms to navigate access to appropriate health care. For the purposes of this study, health care includes primary health care settings such as interactions with family doctors, nurse practitioners, community health centres, and student health services, as a way to centre specific experiences. Through group discussion, we will discuss the processes through which you navigate the health care services you interact with. I am particularly interested in how race and gender identity intersect in ways that impact your health care seeking experience.

I invite you to participate in an online focus group of Black women-identifying McMaster students and alumni to collaborate in the decision-making around a proposed online health care-related platform for Black women to access and contribute to based on their lived experiences. It is intended that we share suggestions about what would be helpful for us to navigate health care online in ways that reflect the knowledge and methods of support and advocacy explored in the focus group.

This research begins as part of a graduate thesis; however, creation of an online platform is hoped to continue beyond the research as a means to create opportunities to broaden the network of Black women on campus to engage with each other and outside organizations and communities working to advance Black health.

Procedures involved in the Research

If you choose to participate in this project, you will take part in 1 online focus group. The online focus group will be facilitated by myself and will consist of 6-8 Black woman-identifying students on Zoom Video Communications (Zoom). I will participate through video for facilitative purposes; however, you can participate through audio or video. You will be sent a website link via email to the meeting where you will create a username that you feel comfortable using and being called for the entirety of the meeting. You will be asked questions about your experiences in health care settings and your suggestions for online platform based in support and advocacy and geared towards Black female health and health care. The following questions are expected to be asked and can be reviewed prior to the focus group:

1) How do you think/feel being a Black woman impacts your reality in health care settings?
2) Have you had interactions in health care settings where you experienced racism, sexism, discrimination, neglect, underrepresentation, marginalization, etc.?
3) If you have experienced these, have these experiences affected your trust towards health care professionals/settings? How?
4) Have you advocated for yourself or your peer(s) as it relates to your health or healthcare? What was that experience like?
5) What platforms, resources or people do you use or contact to gain information about health and health care? Why?
6) What should be the focus of an online platform about Black female health?
7) What would be helpful for you in an online platform geared towards helping you navigate health care spaces? (i.e. an interactive section where women can share tips/strategies, links to culturally responsive health care providers, etc.) Why are these important?

The focus group should take approximately 2 hours to complete. With your permission, focus groups will be audio-recorded on a digital voice recorder. Handwritten notes may also be taken to support audio recordings. Audio, written and transcribed files will be encrypted and stored on a password protected USB drive and stored in a locked home office. The information you provide will be kept in a locked desk that only I and Saara Greene will have access to.

Potential Harms, Risks or Discomforts:

There are risks involved in participating in this study that you should be know and consider before taking part in the focus group process. You may feel uncomfortable, anxious or uneasy when answering questions about your personal experiences in health care settings. You may worry about disclosing your feelings, thoughts, opinions, and/or how others will react to what you say. Additionally, you may experience stress when listening to other participants experiences if they talk about racism, sexism, discrimination, neglect, underrepresentation, marginalization, etc.

In an effort to relieve some of these stresses, you are not required to answer questions that you do not want to answer. Silence or withdrawal from the study will not be penalized, and you will still receive compensation for participating. If while discussing sensitive topics you would like to take a break, please do so. I will be happy to check in with you at a later time. You may request to stop audio recording at any time during the focus group. Additionally, you will be given a resource list of services in the Hamilton community to access should you need them for support, safety and comfort.

A script detailing consent will be read to you prior to the start of the focus group in an attempt to secure your privacy and confidentiality. Participants are not to share information about the focus group elsewhere; however, there are social risks involved in this study as this cannot be guaranteed. Also, your personal information or stories may be shared, which may lead to you being identifiable. I will take all possible measures to protect your privacy and confidentiality to avoid the social risks defined above. Please see the confidentiality section below for more information.

Potential Benefits

Participants may not benefit directed from participation in this study. It is intended that this study will provide an opportunity to share, bond, connect and network with a group of women with similar experiences in an intentional, safer space. The project intends to draw on strengths women already use to take up health care and in doing so, it is hoped this is a healing and empowering process. Additionally, the opportunity to discuss what you would need in a platform aimed to prioritize the needs and wants of women is intended to make you feel represented and included, as well as supported by your peers. You are contributing to the construction of new knowledge that will be used beyond your university community in tackling issues of Black female health.

Compensation

A $10 virtual Visa gift card will be sent to participants after the completion of the online focus group.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. I ask that you respect the privacy and confidentiality of the other participants in the focus group. You are not permitted to share the identities of group members, or information about what is shared.

Your name or any other information that would allow you to be identified will not be used or recorded. This excludes the fact that you are Black woman at McMaster University. Since the Black community at McMaster University is relatively small, others may be able to identify you on the basis of references you make or the stories you tell. Members of the focus group are asked to keep what is said confidential, but I cannot guarantee that they will do so. Please keep this in mind when deciding what to share in the focus group.

The consent log with your email and (user)name is the only piece of data that will name you as a participant in the study and will be stored in a locked home office. The information you provide will be kept in a locked desk where only I and Saara Greene will have access to it. The data will be destroyed by September 30, 2020.

Once the study is complete, the audio recording of the focus group and any additional handwritten notes taken will be deleted and shredded by September 30, 2020. The focus group will be maintained in the form of the written transcriptions with no identifying information and will be deleted 3 months after the completion of the project. The consent log will also be shredded 3 months after the study is completed.

Legally Required Disclosure

Although I will protect your privacy as outlined above, if the law requires it, I may be required to reveal certain personal information. As the facilitator of the research project, I cannot breach your confidentiality for any reason other than for legal purposes, or if you disclose personal information about detailing significant harm to yourself or others.

Participation and Withdrawal

Your participation in this study is voluntary. If you decide to be part of the study, you can withdraw from the focus group for whatever reason and at any time. If you want to stop being in the focus group, you may stay and stop talking or you may leave the meeting with no consequence. It will not be possible for you to pull out comments already spoken from the flow of the conversation because of the interconnected nature of this type of group discussion where a person's comments can stimulate the sharing of comments made by others in the group.

If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions, you do not have to, and you can still be in the study.

Information about the Study Results

I expect to have this study completed by September 30, 2020. If you would like a brief summary of the results, please let me know how you would like it sent to you at the end of this form or via email.

Questions about the Study

If you have questions or need more information about the study itself, please contact Ranece Gordon-Folkes at:

gordonra@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

C/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

APPENDIX 4:

Black Women's Visions for Peer-Advocacy and Support in Health Care

Researcher: Ranece Gordon-Folkes

Oral Consent Script

Focus Group Discussion

Introduction

Hello. I'm Ranece Gordon and I am conducting this focus group about Black women's interactions with health care services. I'm conducting this as part of my Master's thesis research at McMaster University's School of Social. I'm working under the direction Dr. Saara Greene, director of the School of Social Work.

You are all here because you expressed interest in this study through email and I'm entirely grateful!

What will happen during the focus group?

We will be engaging in an online focus group that will take about 2 hours. We will take a 15-20 minutes at the halfway point. I will ask you questions about your experiences in primary health care settings such as with your family doctor, nurse practitioners, community health centres, and student health services. The focus group will be audio recorded with a digital recorder and not on Zoom to ensure the recording can be deleted once the study in complete. I will also be taking handwritten notes without identifying information to support the audio recording.

Risks

There are risks involved in participating in this study that you should be know and consider before taking part in the focus group process. You may feel uncomfortable, anxious or uneasy when answering questions about your personal experiences in health care settings. You may worry about disclosing your feelings, thoughts, opinions, and/or how others will react to what you say. Additionally, you may experience stress when listening to other participants experiences if they talk about racism, sexism, discrimination, neglect, underrepresentation, marginalization, etc.

You are not required to answer questions that you do not want to answer. Silence or withdrawal from the study will not be penalized, and you will still receive compensation for participating. If while discussing sensitive topics you would like to take a break, please do so. I will be happy to check in with you at a later time. You may request to stop audio recording at any time during the focus group.

Benefits

You may not benefit directed from participation in this study. It is intended that this study will provide an opportunity to share, bond, connect and network with a group of women with similar experiences in an intentional, safer space. The project intends to draw on strengths women already use to take up health care and in doing so, it is hoped this is a healing and empowering process.

Compensation

You will be sent a $10 virtual Visa gift card upon completion of this focus group.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. I ask that you respect the privacy and confidentiality of the other participants in the focus group. You are not permitted to share the identities of group members, or information about what is shared. You are not permitted to audio or video record the focus group on Zoom or your own devices.

Your name or any other information that would allow you to be identified will not be used or recorded. This excludes the fact that you are Black woman at McMaster University. Since the Black community at McMaster University is relatively small, others may be able to identify you on the basis of references you make or the stories you tell. Members of the focus group are asked to keep what is said confidential, but I cannot guarantee that they will do so. Please keep this in mind when deciding what to share in the focus group.

Legally Required Disclosure

Although I will protect your privacy as outlined above, if the law requires it, I may be required to reveal certain personal information. As the facilitator of the research project, I cannot breach your confidentiality for any reason other than for legal purposes, or if you disclose personal information about detailing significant harm to yourself or others.

Participation and Withdrawal

Your participation in this study is voluntary. If you decide to be part of the study, you can withdraw from the focus group for whatever reason and at any time. If you want to stop being in the focus group, you may stay and stop talking or you may leave the meeting with no consequence. If you do not want to answer some of the questions, you do not have to, and you can still be in the study.

Consent questions:

- Do you agree that the interview can be audio recorded?
- Do you agree to have direct, anonymous quotations of your conversations with the facilitator and other participants used in the thesis report?
- Do you agree to be contacted about a follow-up consultation and understand that you can always decline the request?
- Would you like to receive study results? If yes, how?
- Do you have any questions or would like any additional details? *[Answer questions.]*
- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?

[If yes, begin the interview.]

[If no, thank the participant for her time.]

[*Document verbal consent in oral consent log – focus group discussion*.]

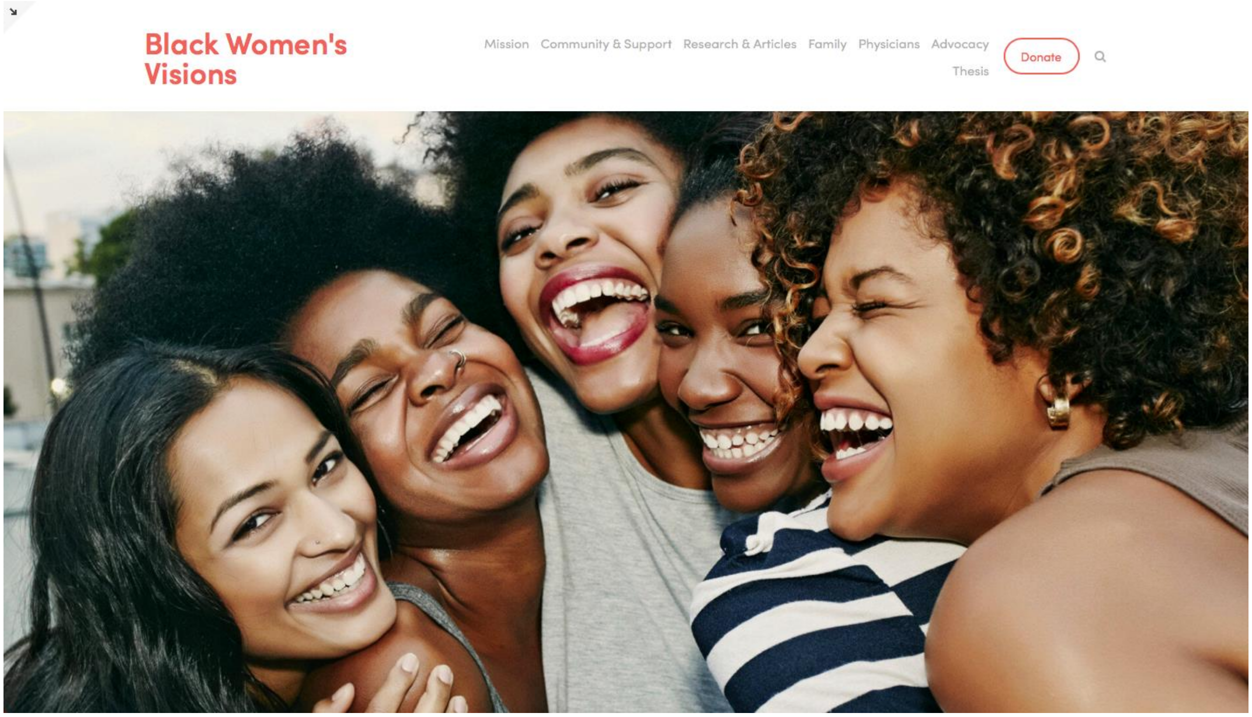
APPENDIX 5:

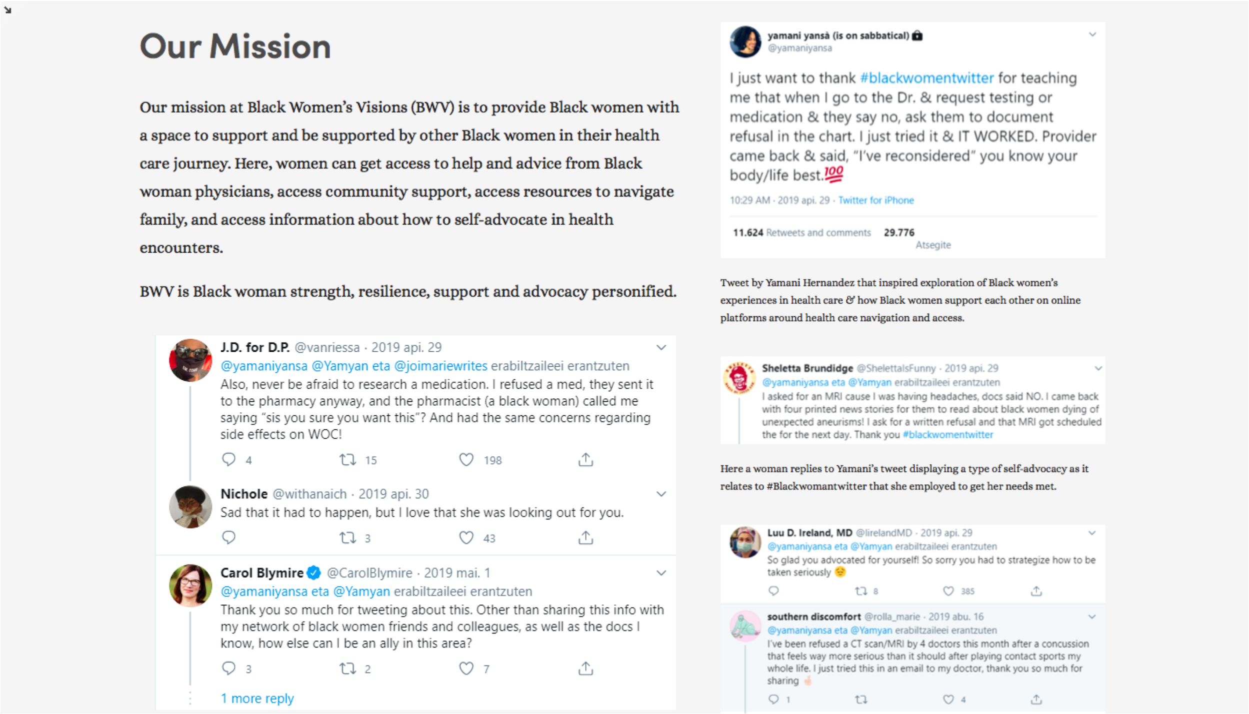
RESEARCHER’S LOG FOR RECORDING VERBAL CONSENT

Focus group discussion

Date of focus group: May 1, 2020

Participants (user)name	**Participant’s email**	**Consent to participation in study (Yes/No)**	**Consent to audio recording/note taking (Yes/No)**	**Consent to follow up consultation (Yes/No)**	**Consent to receive study results? (Yes/No)**	**Method for study results to be sent (Email/Address)**





Our Mission

Our mission at Black Women's Visions (BWV) is to provide Black women with a space to support and be supported by other Black women in their health care journey. Here, women can get access to help and advice from Black woman physicians, access community support, access resources to navigate family, and access information about how to self-advocate in health encounters.

BWV is Black woman strength, resilience, support and advocacy personified.

J.D. for D.P. @vanriessa · 2019 api. 29
@yamaniyansa @Yamyan eta @joimariewrites erabiltzaileei erantzuten
Also, never be afraid to research a medication. I refused a med, they sent it to the pharmacy anyway, and the pharmacist (a black woman) called me saying "sis you sure you want this"? And had the same concerns regarding side effects on WOC!
4 15 198

Nichole @withanaich · 2019 api. 30
Sad that it had to happen, but I love that she was looking out for you.
3 43

Carol Blymire @CarolBlymire · 2019 mai. 1
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
Thank you so much for tweeting about this. Other than sharing this info with my network of black women friends and colleagues, as well as the docs I know, how else can I be an ally in this area?
3 2 7

1 more reply

yamani yansà (is on sabbatical)
@yamaniyansa

I just want to thank #blackwomentwitter for teaching me that when I go to the Dr. & request testing or medication & they say no, ask them to document refusal in the chart. I just tried it & IT WORKED. Provider came back & said, "I've reconsidered" you know your body/life best.💯

10:29 AM · 2019 api. 29 · Twitter for iPhone

11.624 Retweets and comments **29.776** Atsegite

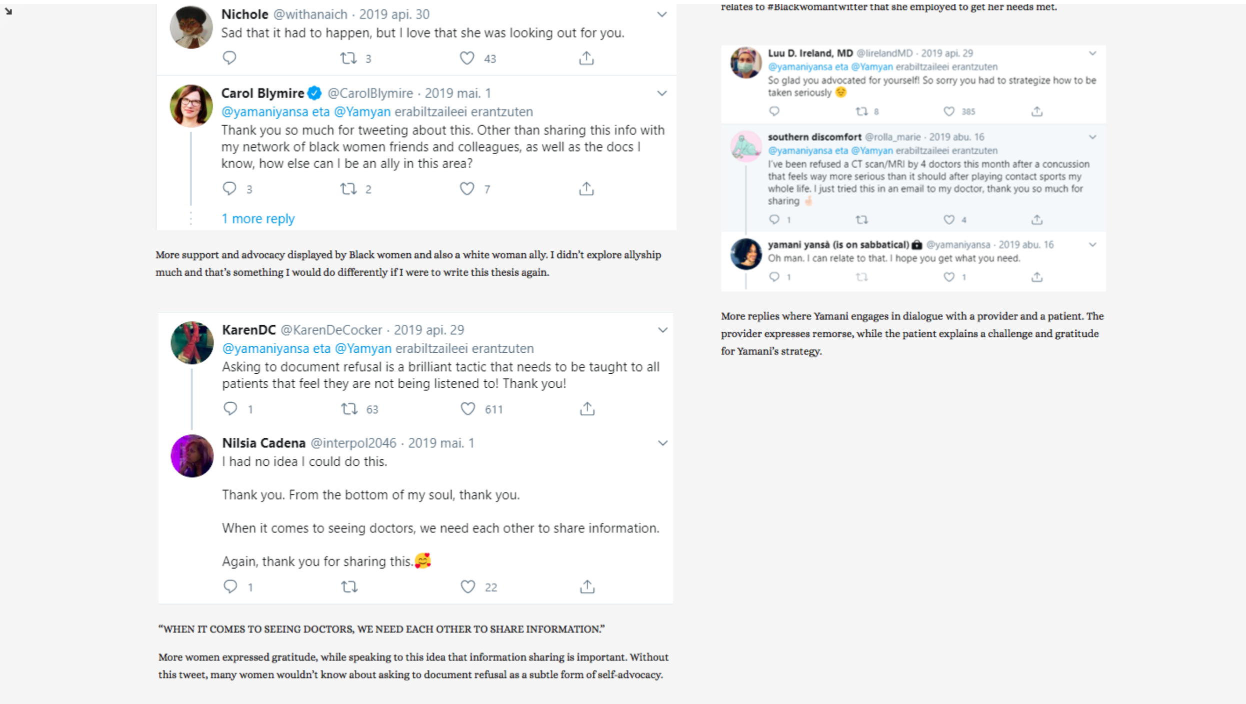
Tweet by Yamani Hernandez that inspired exploration of Black women's experiences in health care & how Black women support each other on online platforms around health care navigation and access.

Sheletta Brundidge @ShelettaIsFunny · 2019 api. 29
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
I asked for an MRI cause I was having headaches, docs said NO. I came back with four printed news stories for them to read about black women dying of unexpected aneurisms! I ask for a written refusal and that MRI got scheduled the for the next day. Thank you #blackwomentwitter

Here a woman replies to Yamani's tweet displaying a type of self-advocacy as it relates to #Blackwomantwitter that she employed to get her needs met.

Luu D. Ireland, MD @lirelandMD · 2019 api. 29
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
So glad you advocated for yourself! So sorry you had to strategize how to be taken seriously 😔
8 385

southern discomfort @rolla_marie · 2019 abu. 16
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
I've been refused a CT scan/MRI by 4 doctors this month after a concussion that feels way more serious than it should after playing contact sports my whole life. I just tried this in an email to my doctor, thank you so much for sharing 🤞
1 4



Nichole @withanaich · 2019 api. 30
Sad that it had to happen, but I love that she was looking out for you.
3 43

Carol Blymire @CarolBlymire · 2019 mai. 1
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
Thank you so much for tweeting about this. Other than sharing this info with my network of black women friends and colleagues, as well as the docs I know, how else can I be an ally in this area?
3 2 7
1 more reply

More support and advocacy displayed by Black women and also a white woman ally. I didn't explore allyship much and that's something I would do differently if I were to write this thesis again.

KarenDC @KarenDeCocker · 2019 api. 29
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
Asking to document refusal is a brilliant tactic that needs to be taught to all patients that feel they are not being listened to! Thank you!
1 63 611

Nilsia Cadena @interpol2046 · 2019 mai. 1
I had no idea I could do this.

Thank you. From the bottom of my soul, thank you.

When it comes to seeing doctors, we need each other to share information.

Again, thank you for sharing this.🥰
1 22

"WHEN IT COMES TO SEEING DOCTORS, WE NEED EACH OTHER TO SHARE INFORMATION."

More women expressed gratitude, while speaking to this idea that information sharing is important. Without this tweet, many women wouldn't know about asking to document refusal as a subtle form of self-advocacy.

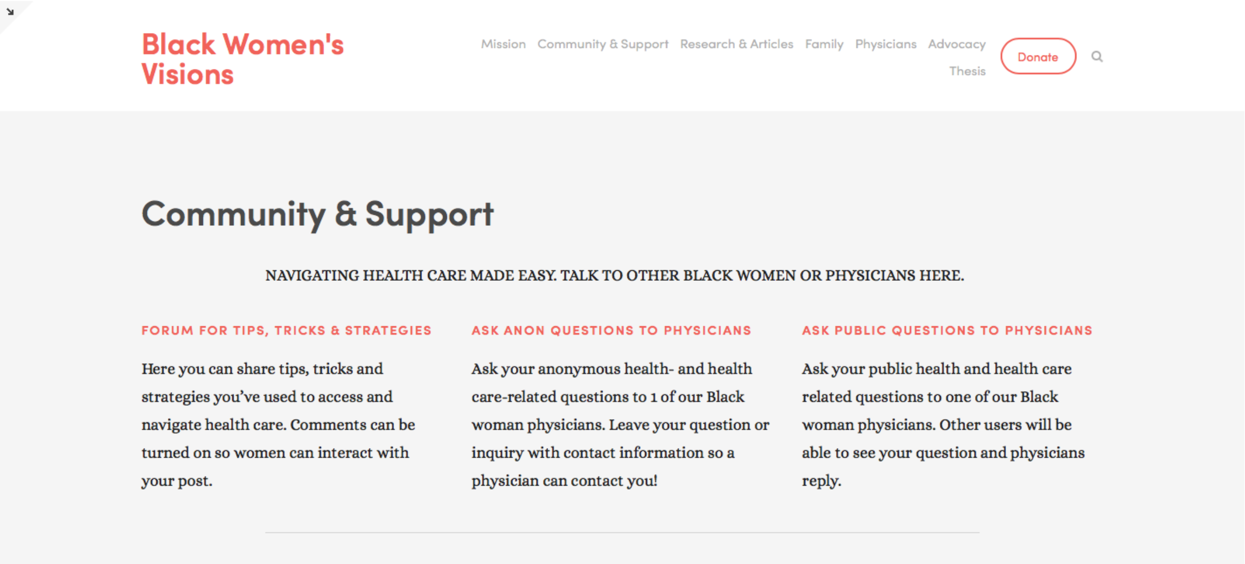
relates to #Blackwomantwitter that she employed to get her needs met.

Luu D. Ireland, MD @lirelandMD · 2019 api. 29
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
So glad you advocated for yourself! So sorry you had to strategize how to be taken seriously 😔
8 385

southern discomfort @rolla_marie · 2019 abu. 16
@yamaniyansa eta @Yamyan erabiltzaileei erantzuten
I've been refused a CT scan/MRI by 4 doctors this month after a concussion that feels way more serious than it should after playing contact sports my whole life. I just tried this in an email to my doctor, thank you so much for sharing 🤞
1 4

yamani yansà (is on sabbatical) 💼 @yamaniyansa · 2019 abu. 16
Oh man. I can relate to that. I hope you get what you need.
1 1

More replies where Yamani engages in dialogue with a provider and a patient. The provider expresses remorse, while the patient explains a challenge and gratitude for Yamani's strategy.



Community & Support

NAVIGATING HEALTH CARE MADE EASY. TALK TO OTHER BLACK WOMEN OR PHYSICIANS HERE.

FORUM FOR TIPS, TRICKS & STRATEGIES

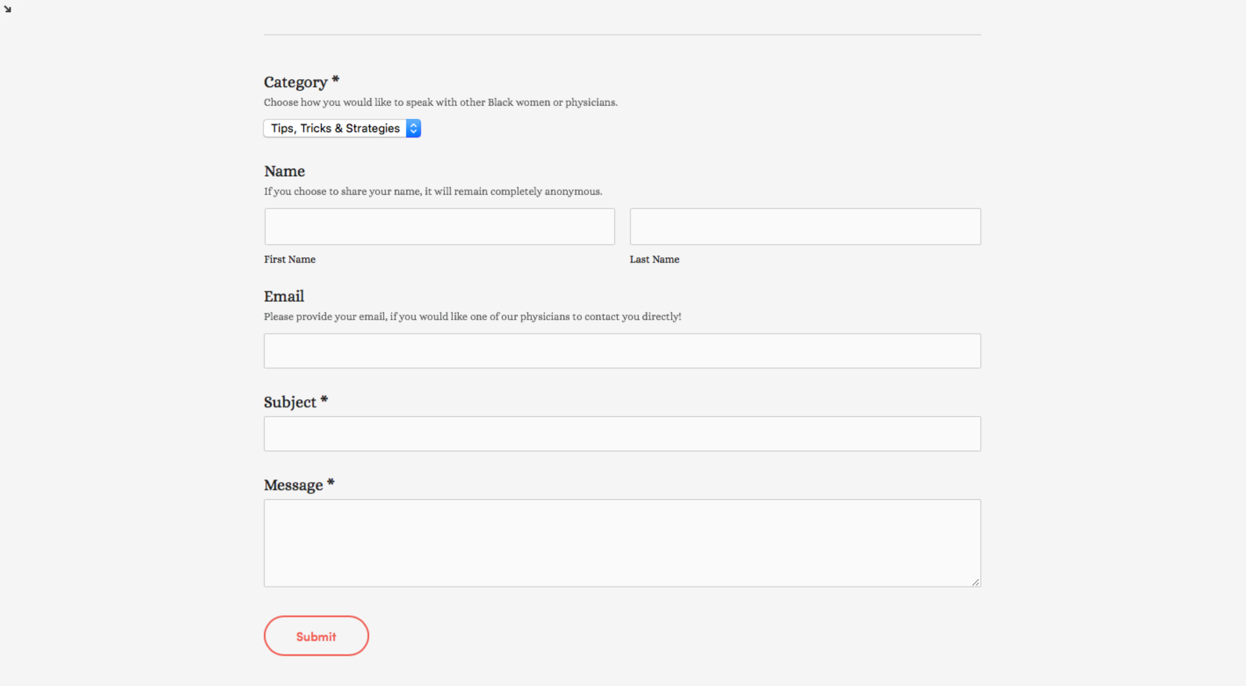
Here you can share tips, tricks and strategies you've used to access and navigate health care. Comments can be turned on so women can interact with your post.

ASK ANON QUESTIONS TO PHYSICIANS

Ask your anonymous health- and health care-related questions to 1 of our Black woman physicians. Leave your question or inquiry with contact information so a physician can contact you!

ASK PUBLIC QUESTIONS TO PHYSICIANS

Ask your public health and health care related questions to one of our Black woman physicians. Other users will be able to see your question and physicians reply.



Category *

Choose how you would like to speak with other Black women or physicians.

Tips, Tricks & Strategies

Name

If you choose to share your name, it will remain completely anonymous.

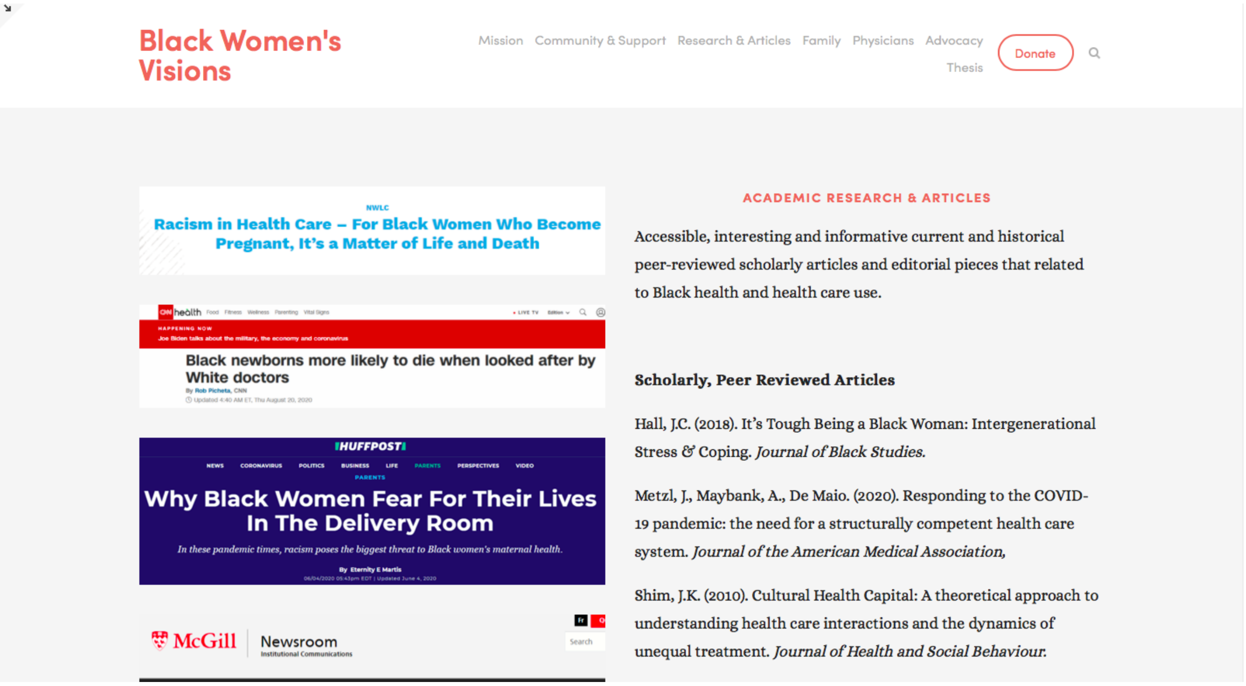
First Name	Last Name

Email

Please provide your email, if you would like one of our physicians to contact you directly!

Subject *

Message *



NWLC

Racism in Health Care – For Black Women Who Become Pregnant, It's a Matter of Life and Death

HAPPENING NOW

Joe Biden talks about the military, the economy and coronavirus

Black newborns more likely to die when looked after by White doctors

By Rob Picheta, CNN

Updated 4:40 AM ET, Thu August 20, 2020

Why Black Women Fear For Their Lives In The Delivery Room

In these pandemic times, racism poses the biggest threat to Black women's maternal health.

By Eternity E Martis

06/04/2020 05:43pm EDT | Updated June 4, 2020

ACADEMIC RESEARCH & ARTICLES

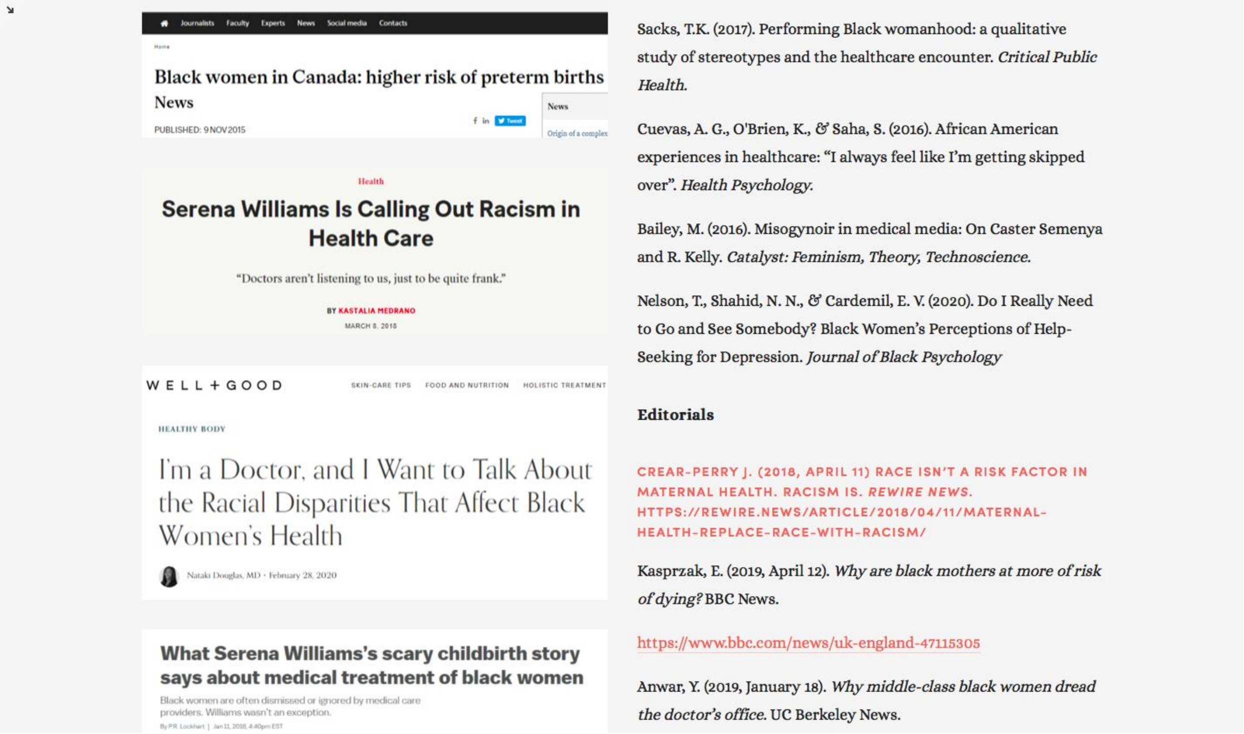
Accessible, interesting and informative current and historical peer-reviewed scholarly articles and editorial pieces that related to Black health and health care use.

Scholarly, Peer Reviewed Articles

Hall, J.C. (2018). It's Tough Being a Black Woman: Intergenerational Stress & Coping. *Journal of Black Studies.*

Metzl, J., Maybank, A., De Maio. (2020). Responding to the COVID-19 pandemic: the need for a structurally competent health care system. *Journal of the American Medical Association,*

Shim, J.K. (2010). Cultural Health Capital: A theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *Journal of Health and Social Behaviour.*



Black women in Canada: higher risk of preterm births

News

PUBLISHED: 9 NOV 2015

Health

Serena Williams Is Calling Out Racism in Health Care

"Doctors aren't listening to us, just to be quite frank."

BY KASTALIA MEDRANO

MARCH 8, 2018

WELL+GOOD

HEALTHY BODY

I'm a Doctor, and I Want to Talk About the Racial Disparities That Affect Black Women's Health

Nataki Douglas, MD · February 28, 2020

What Serena Williams's scary childbirth story says about medical treatment of black women

Black women are often dismissed or ignored by medical care providers. Williams wasn't an exception.

By P.R. Lockhart | Jan 11, 2018, 4:40pm EST

Sacks, T.K. (2017). Performing Black womanhood: a qualitative study of stereotypes and the healthcare encounter. *Critical Public Health.*

Cuevas, A. G., O'Brien, K., & Saha, S. (2016). African American experiences in healthcare: "I always feel like I'm getting skipped over". *Health Psychology.*

Bailey, M. (2016). Misogynoir in medical media: On Caster Semenya and R. Kelly. *Catalyst: Feminism, Theory, Technoscience.*

Nelson, T., Shahid, N. N., & Cardemil, E. V. (2020). Do I Really Need to Go and See Somebody? Black Women's Perceptions of Help-Seeking for Depression. *Journal of Black Psychology*

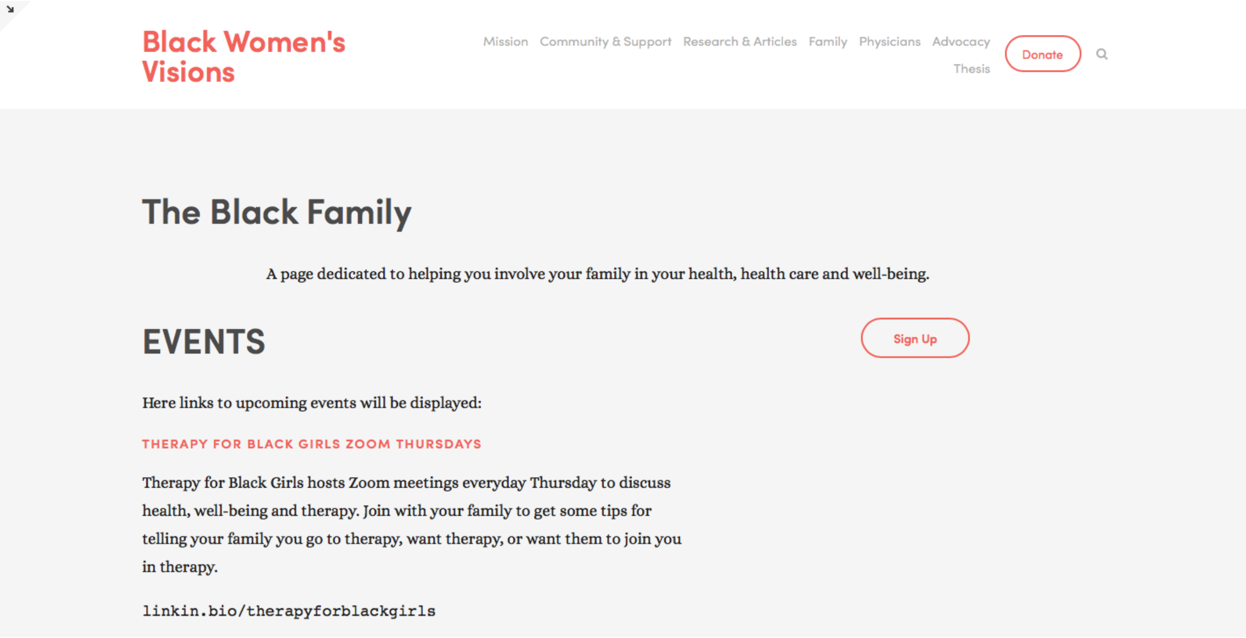
Editorials

CREAR-PERRY J. (2018, APRIL 11) RACE ISN'T A RISK FACTOR IN MATERNAL HEALTH. RACISM IS. *REWIRE NEWS*. HTTPS://REWIRE.NEWS/ARTICLE/2018/04/11/MATERNAL-HEALTH-REPLACE-RACE-WITH-RACISM/

Kasprzak, E. (2019, April 12). *Why are black mothers at more of risk of dying?* BBC News.

https://www.bbc.com/news/uk-england-47115305

Anwar, Y. (2019, January 18). *Why middle-class black women dread the doctor's office.* UC Berkeley News.



The Black Family

A page dedicated to helping you involve your family in your health, health care and well-being.

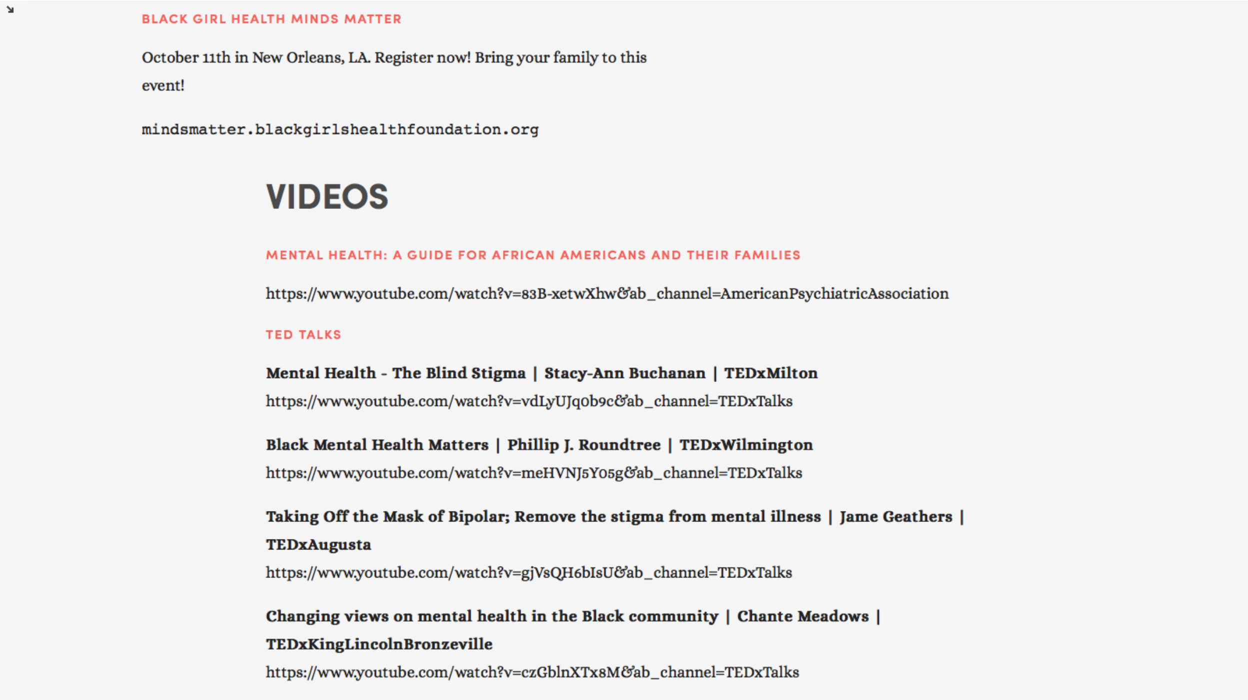
EVENTS

Here links to upcoming events will be displayed:

THERAPY FOR BLACK GIRLS ZOOM THURSDAYS

Therapy for Black Girls hosts Zoom meetings everyday Thursday to discuss health, well-being and therapy. Join with your family to get some tips for telling your family you go to therapy, want therapy, or want them to join you in therapy.

`linkin.bio/therapyforblackgirls`



BLACK GIRL HEALTH MINDS MATTER

October 11th in New Orleans, LA. Register now! Bring your family to this event!

`mindsmatter.blackgirlshealthfoundation.org`

VIDEOS

MENTAL HEALTH: A GUIDE FOR AFRICAN AMERICANS AND THEIR FAMILIES

https://www.youtube.com/watch?v=83B-xetwXhw&ab_channel=AmericanPsychiatricAssociation

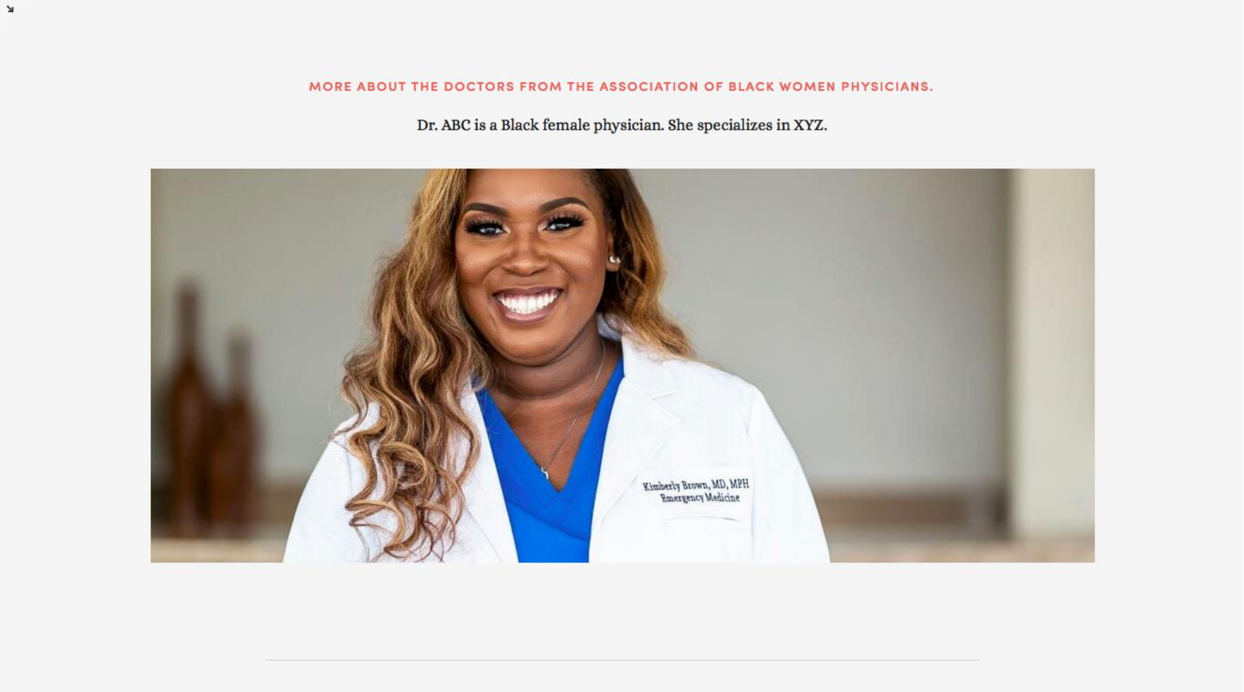
TED TALKS

Mental Health - The Blind Stigma | Stacy-Ann Buchanan | TEDxMilton
https://www.youtube.com/watch?v=vdLyUJq0b9c&ab_channel=TEDxTalks

Black Mental Health Matters | Phillip J. Roundtree | TEDxWilmington
https://www.youtube.com/watch?v=meHVNJ5Y05g&ab_channel=TEDxTalks

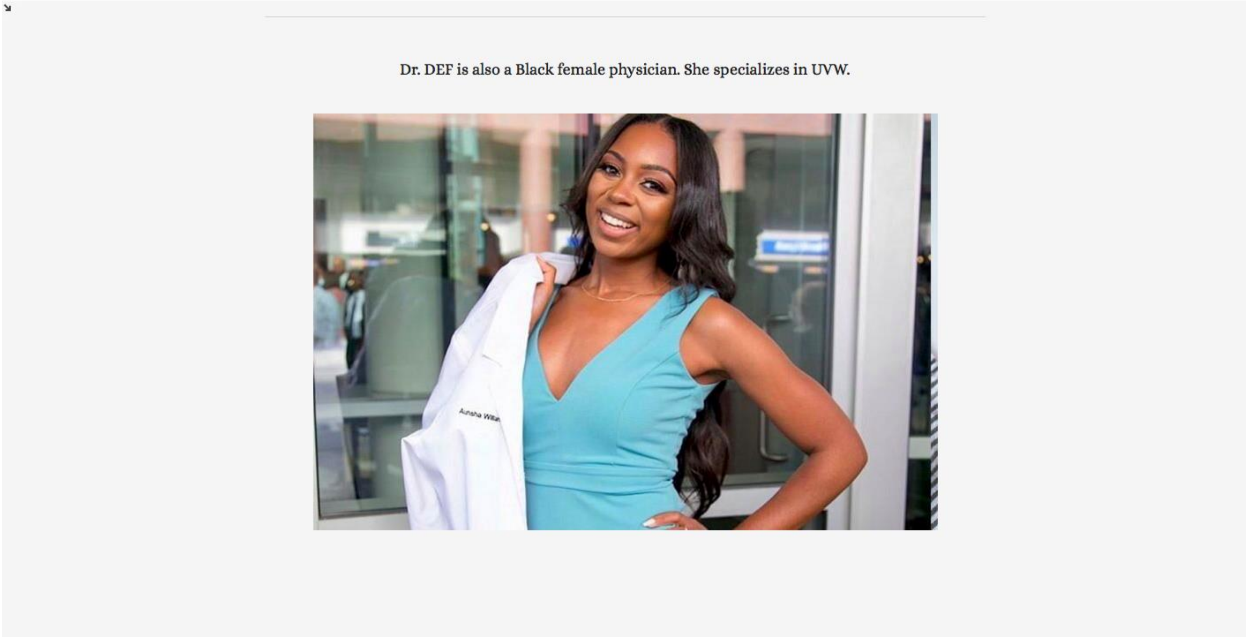
Taking Off the Mask of Bipolar; Remove the stigma from mental illness | Jame Geathers | TEDxAugusta
https://www.youtube.com/watch?v=gjVsQH6bIsU&ab_channel=TEDxTalks

Changing views on mental health in the Black community | Chante Meadows | TEDxKingLincolnBronzeville
https://www.youtube.com/watch?v=czGblnXTx8M&ab_channel=TEDxTalks

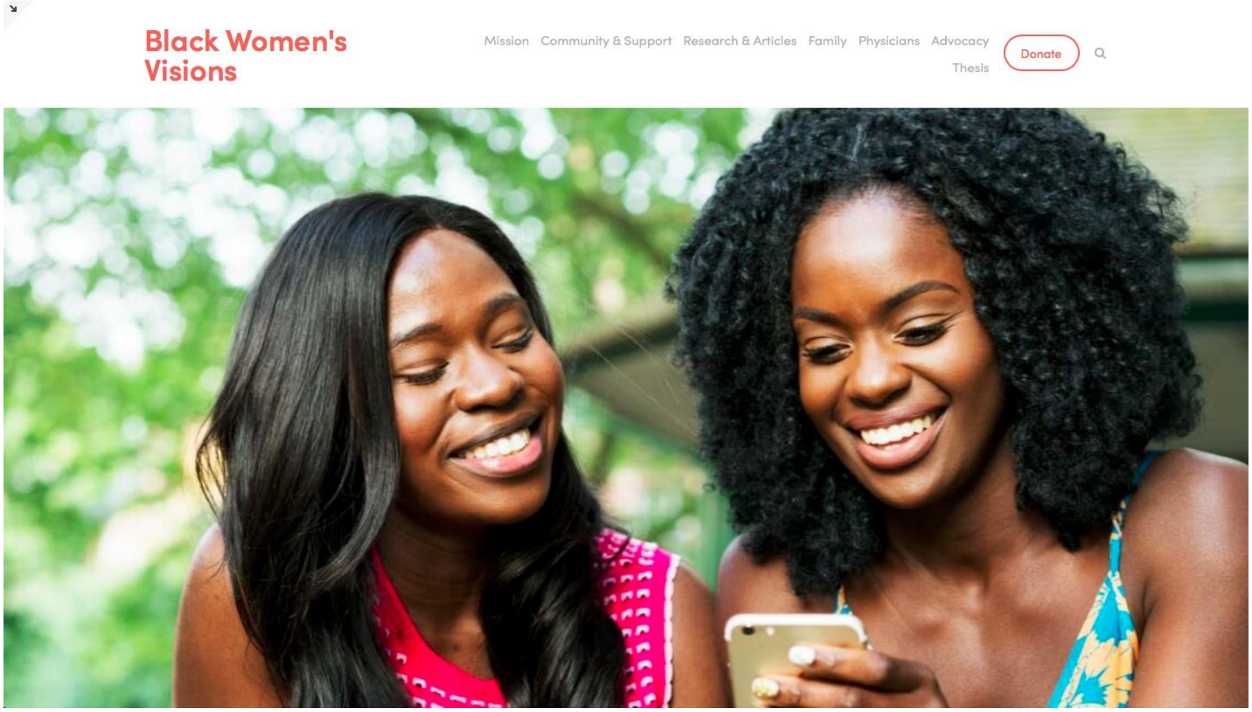


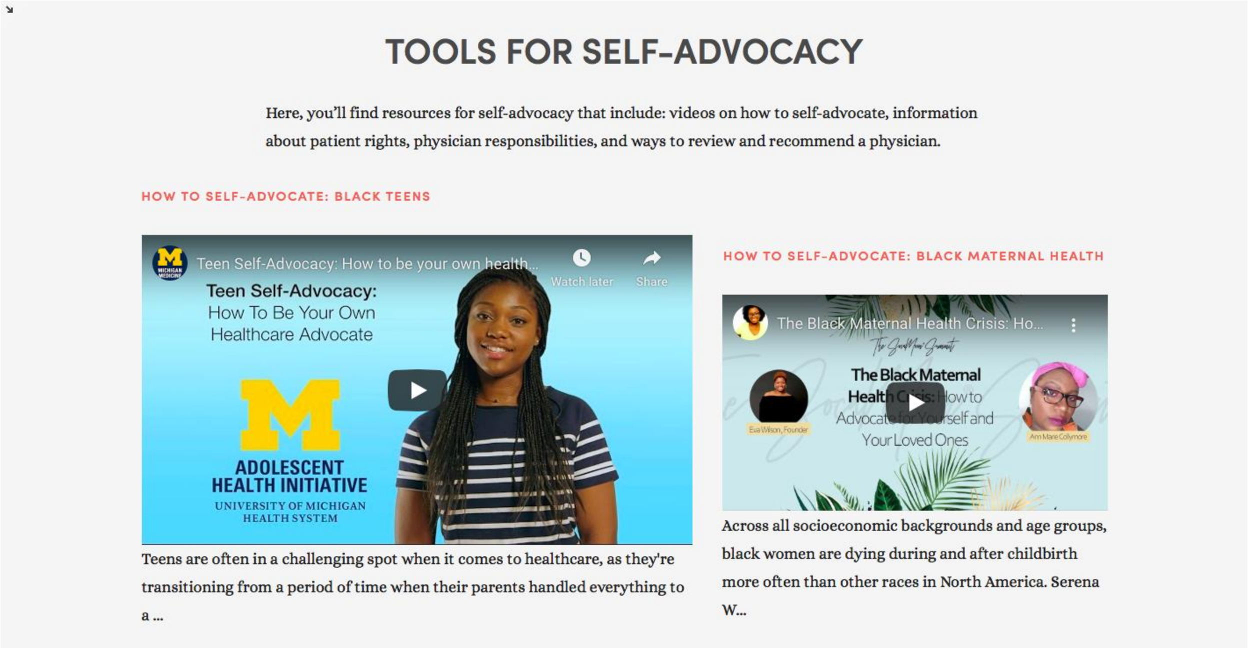
MORE ABOUT THE DOCTORS FROM THE ASSOCIATION OF BLACK WOMEN PHYSICIANS.

Dr. ABC is a Black female physician. She specializes in XYZ.



Dr. DEF is also a Black female physician. She specializes in UVW.





TOOLS FOR SELF-ADVOCACY

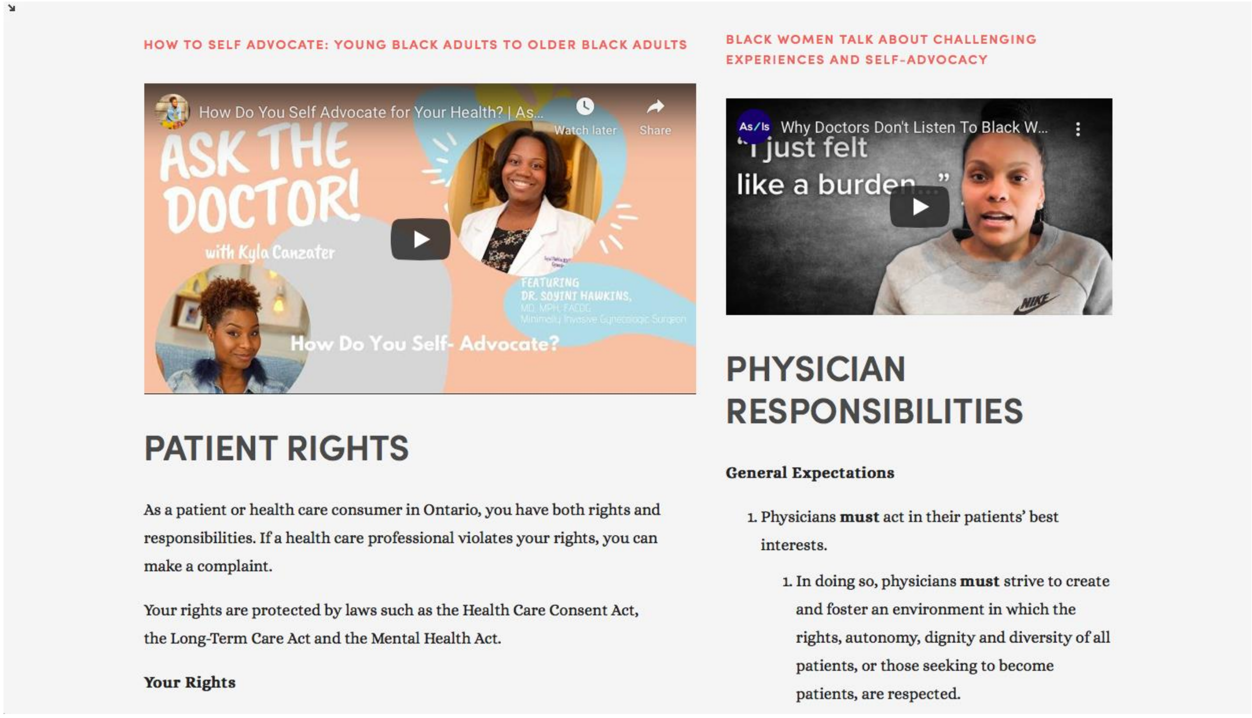
Here, you'll find resources for self-advocacy that include: videos on how to self-advocate, information about patient rights, physician responsibilities, and ways to review and recommend a physician.

HOW TO SELF-ADVOCATE: BLACK TEENS

Teens are often in a challenging spot when it comes to healthcare, as they're transitioning from a period of time when their parents handled everything to a ...

HOW TO SELF-ADVOCATE: BLACK MATERNAL HEALTH

Across all socioeconomic backgrounds and age groups, black women are dying during and after childbirth more often than other races in North America. Serena W...



HOW TO SELF ADVOCATE: YOUNG BLACK ADULTS TO OLDER BLACK ADULTS

BLACK WOMEN TALK ABOUT CHALLENGING EXPERIENCES AND SELF-ADVOCACY

PATIENT RIGHTS

As a patient or health care consumer in Ontario, you have both rights and responsibilities. If a health care professional violates your rights, you can make a complaint.

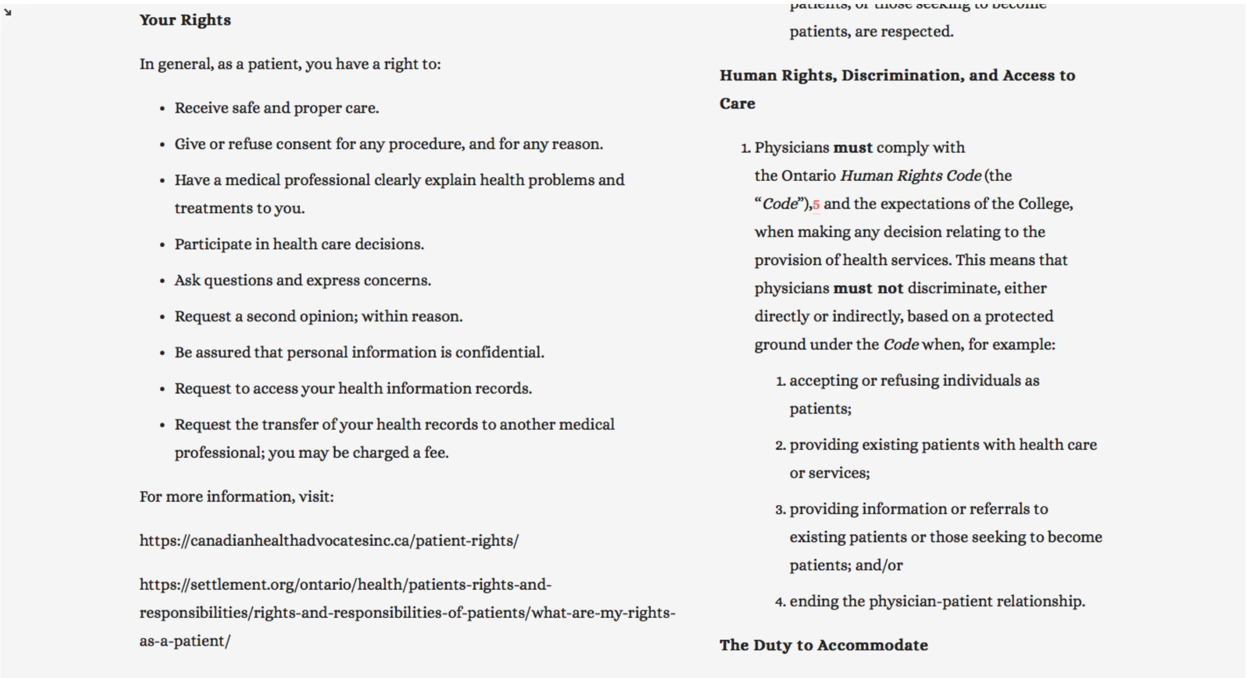
Your rights are protected by laws such as the Health Care Consent Act, the Long-Term Care Act and the Mental Health Act.

Your Rights

PHYSICIAN RESPONSIBILITIES

General Expectations

1. Physicians **must** act in their patients' best interests.
    1. In doing so, physicians **must** strive to create and foster an environment in which the rights, autonomy, dignity and diversity of all patients, or those seeking to become patients, are respected.



Your Rights

In general, as a patient, you have a right to:

- Receive safe and proper care.
- Give or refuse consent for any procedure, and for any reason.
- Have a medical professional clearly explain health problems and treatments to you.
- Participate in health care decisions.
- Ask questions and express concerns.
- Request a second opinion; within reason.
- Be assured that personal information is confidential.
- Request to access your health information records.
- Request the transfer of your health records to another medical professional; you may be charged a fee.

For more information, visit:

https://canadianhealthadvocatesinc.ca/patient-rights/

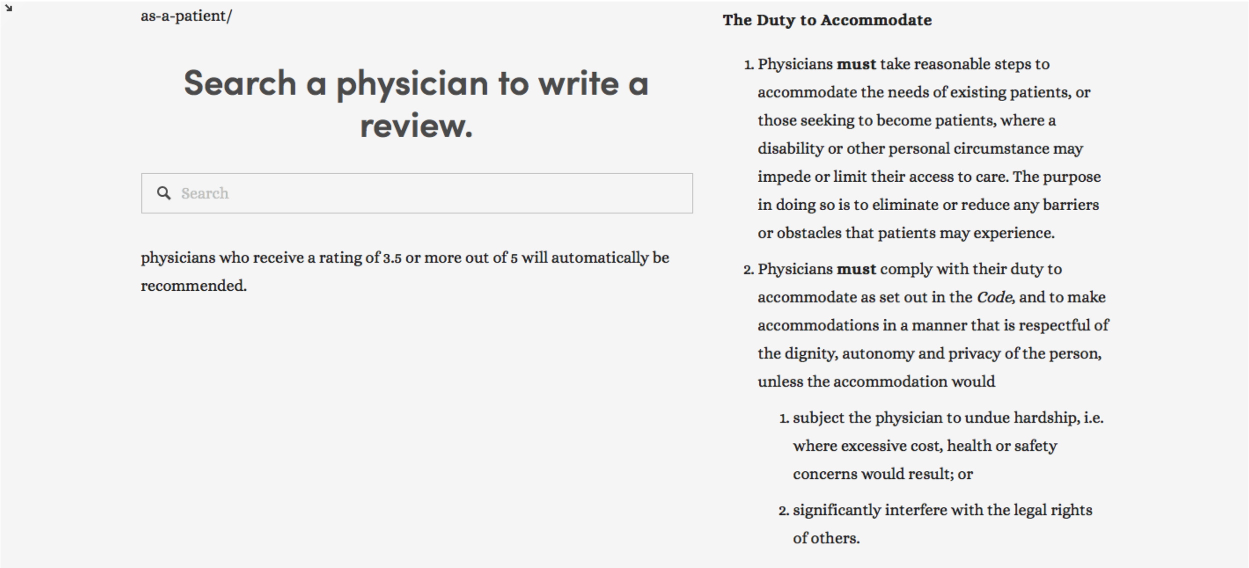
https://settlement.org/ontario/health/patients-rights-and-responsibilities/rights-and-responsibilities-of-patients/what-are-my-rights-as-a-patient/

patients, or those seeking to become patients, are respected.

Human Rights, Discrimination, and Access to Care

1. Physicians **must** comply with the Ontario *Human Rights Code* (the "*Code*"),[5] and the expectations of the College, when making any decision relating to the provision of health services. This means that physicians **must not** discriminate, either directly or indirectly, based on a protected ground under the *Code* when, for example:
    1. accepting or refusing individuals as patients;
    2. providing existing patients with health care or services;
    3. providing information or referrals to existing patients or those seeking to become patients; and/or
    4. ending the physician-patient relationship.

The Duty to Accommodate



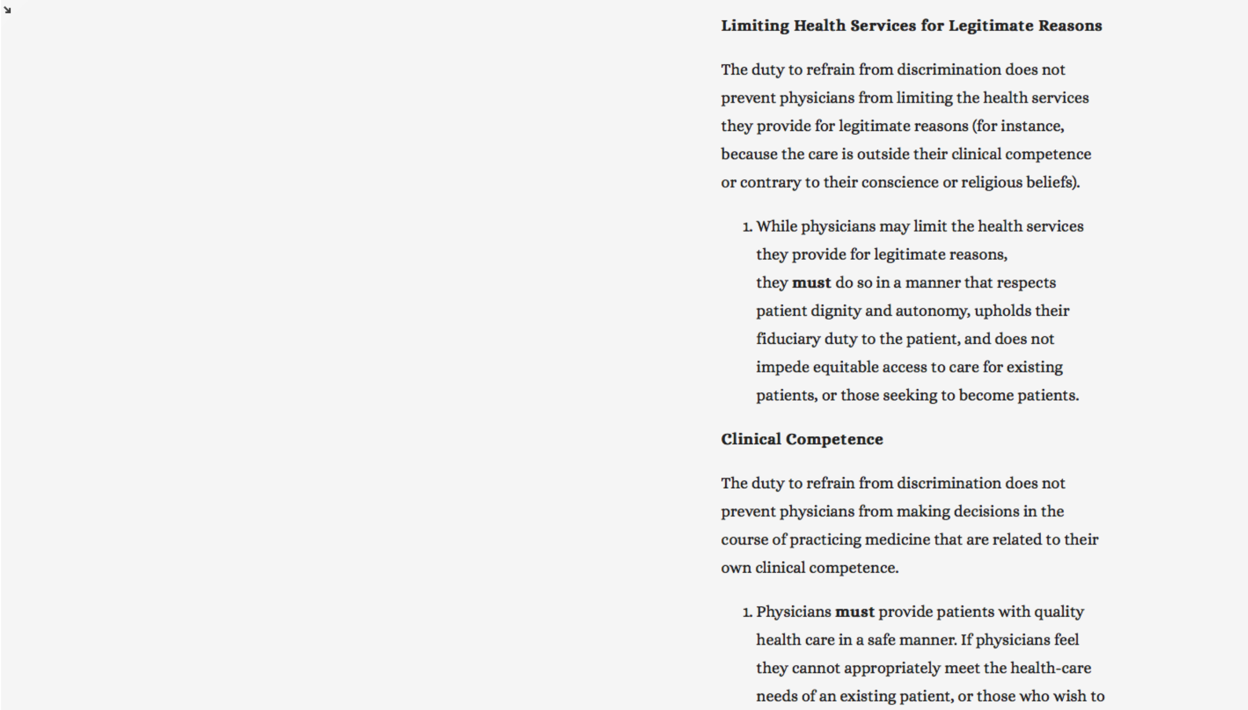
as-a-patient/

Search a physician to write a review.

physicians who receive a rating of 3.5 or more out of 5 will automatically be recommended.

The Duty to Accommodate

1. Physicians **must** take reasonable steps to accommodate the needs of existing patients, or those seeking to become patients, where a disability or other personal circumstance may impede or limit their access to care. The purpose in doing so is to eliminate or reduce any barriers or obstacles that patients may experience.
2. Physicians **must** comply with their duty to accommodate as set out in the *Code*, and to make accommodations in a manner that is respectful of the dignity, autonomy and privacy of the person, unless the accommodation would
    1. subject the physician to undue hardship, i.e. where excessive cost, health or safety concerns would result; or
    2. significantly interfere with the legal rights of others.



Limiting Health Services for Legitimate Reasons

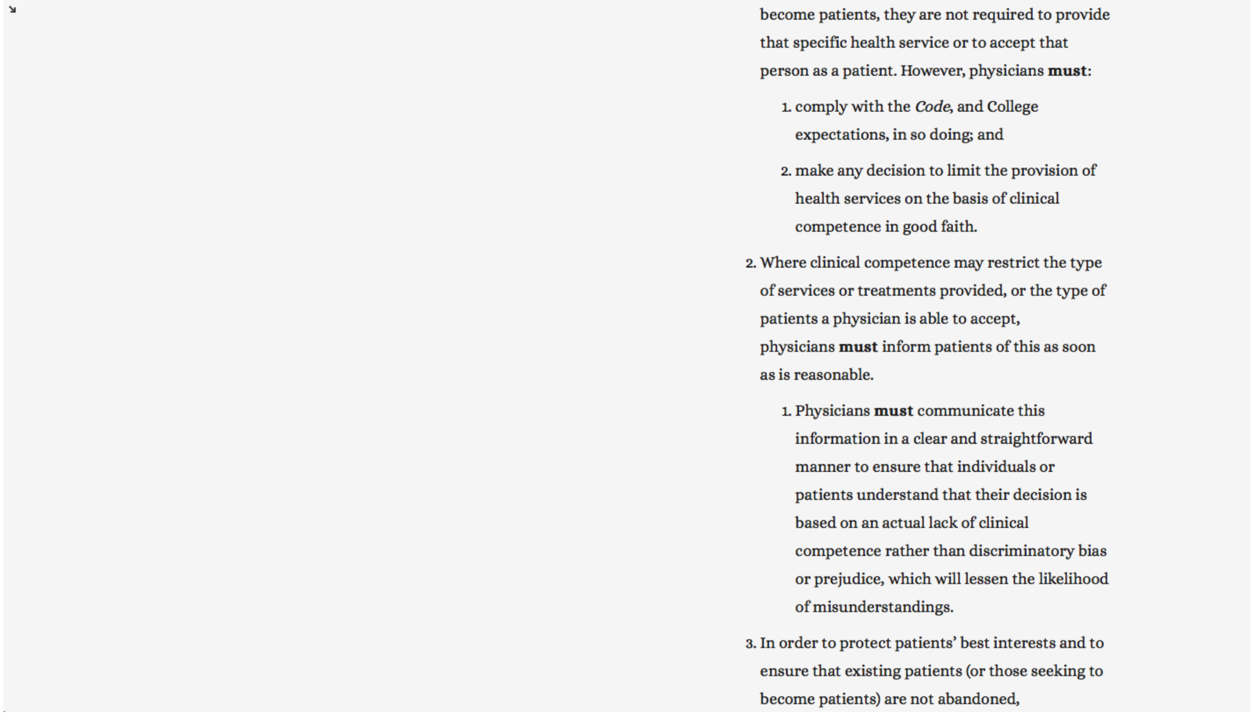
The duty to refrain from discrimination does not prevent physicians from limiting the health services they provide for legitimate reasons (for instance, because the care is outside their clinical competence or contrary to their conscience or religious beliefs).

1. While physicians may limit the health services they provide for legitimate reasons, they **must** do so in a manner that respects patient dignity and autonomy, upholds their fiduciary duty to the patient, and does not impede equitable access to care for existing patients, or those seeking to become patients.

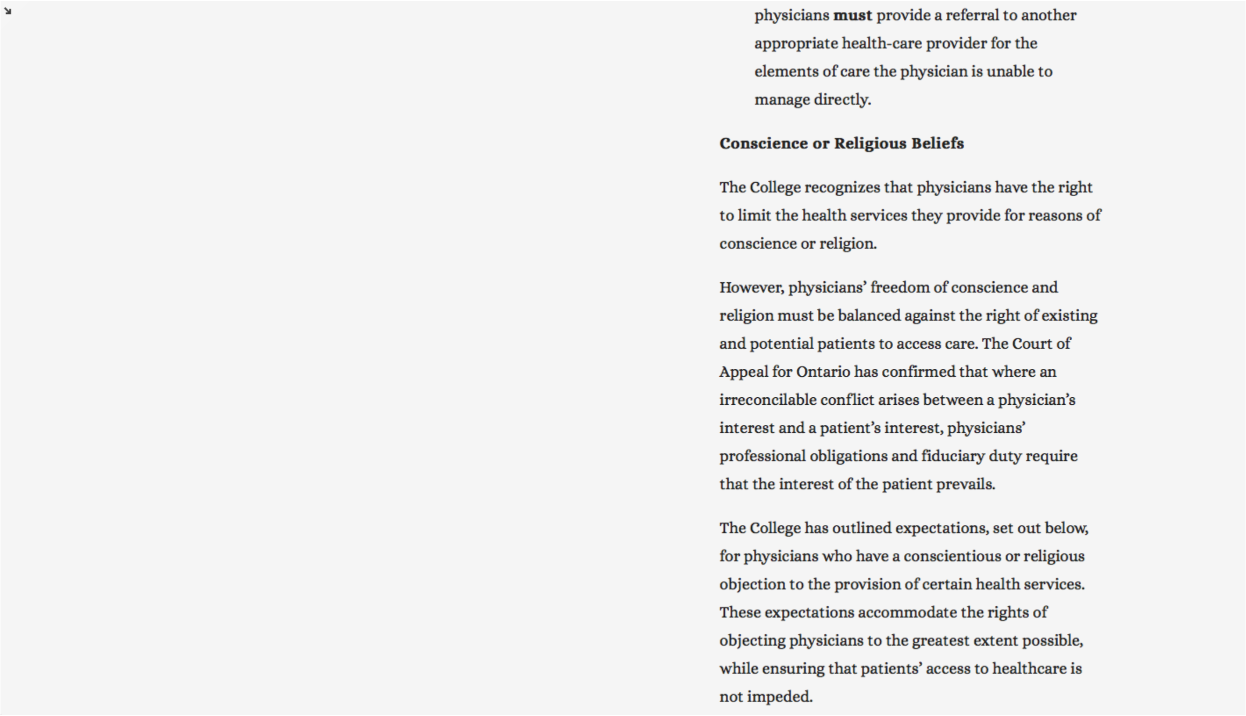
Clinical Competence

The duty to refrain from discrimination does not prevent physicians from making decisions in the course of practicing medicine that are related to their own clinical competence.

1. Physicians **must** provide patients with quality health care in a safe manner. If physicians feel they cannot appropriately meet the health-care needs of an existing patient, or those who wish to



become patients, they are not required to provide that specific health service or to accept that person as a patient. However, physicians **must**:
    1. comply with the *Code*, and College expectations, in so doing; and
    2. make any decision to limit the provision of health services on the basis of clinical competence in good faith.
2. Where clinical competence may restrict the type of services or treatments provided, or the type of patients a physician is able to accept, physicians **must** inform patients of this as soon as is reasonable.
    1. Physicians **must** communicate this information in a clear and straightforward manner to ensure that individuals or patients understand that their decision is based on an actual lack of clinical competence rather than discriminatory bias or prejudice, which will lessen the likelihood of misunderstandings.
3. In order to protect patients' best interests and to ensure that existing patients (or those seeking to become patients) are not abandoned,



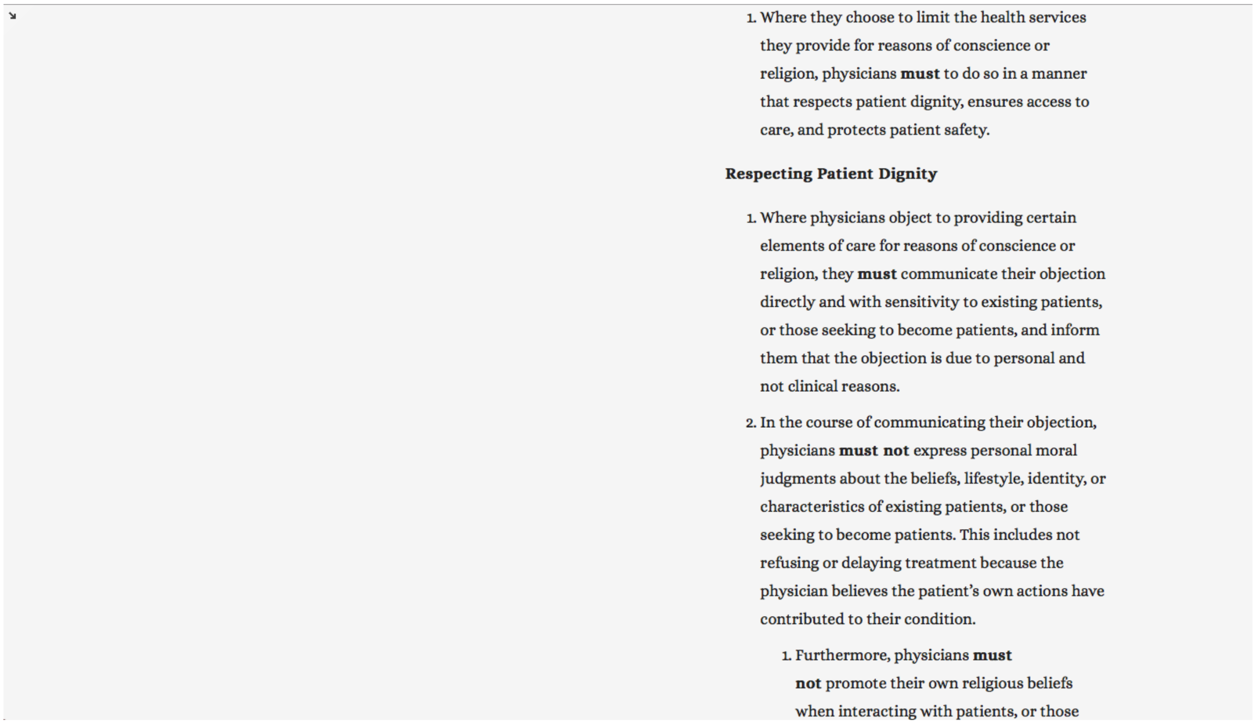
physicians **must** provide a referral to another appropriate health-care provider for the elements of care the physician is unable to manage directly.

Conscience or Religious Beliefs

The College recognizes that physicians have the right to limit the health services they provide for reasons of conscience or religion.

However, physicians' freedom of conscience and religion must be balanced against the right of existing and potential patients to access care. The Court of Appeal for Ontario has confirmed that where an irreconcilable conflict arises between a physician's interest and a patient's interest, physicians' professional obligations and fiduciary duty require that the interest of the patient prevails.

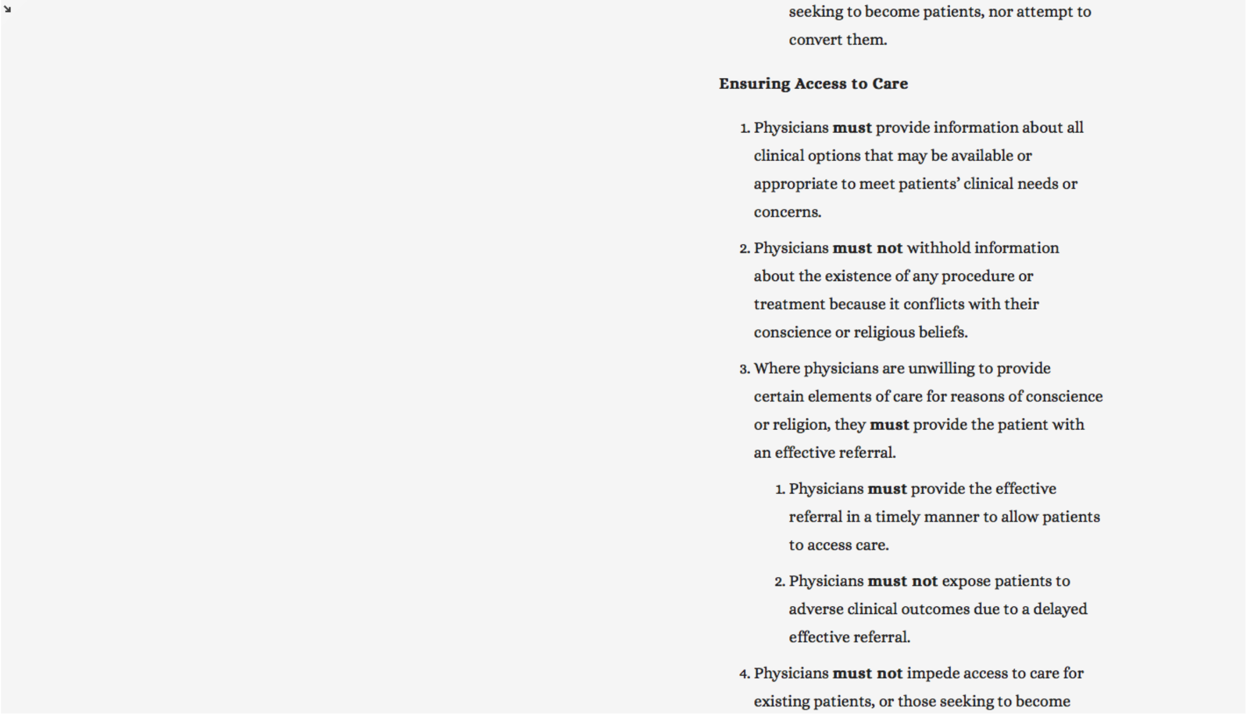
The College has outlined expectations, set out below, for physicians who have a conscientious or religious objection to the provision of certain health services. These expectations accommodate the rights of objecting physicians to the greatest extent possible, while ensuring that patients' access to healthcare is not impeded.



1. Where they choose to limit the health services they provide for reasons of conscience or religion, physicians **must** to do so in a manner that respects patient dignity, ensures access to care, and protects patient safety.

Respecting Patient Dignity

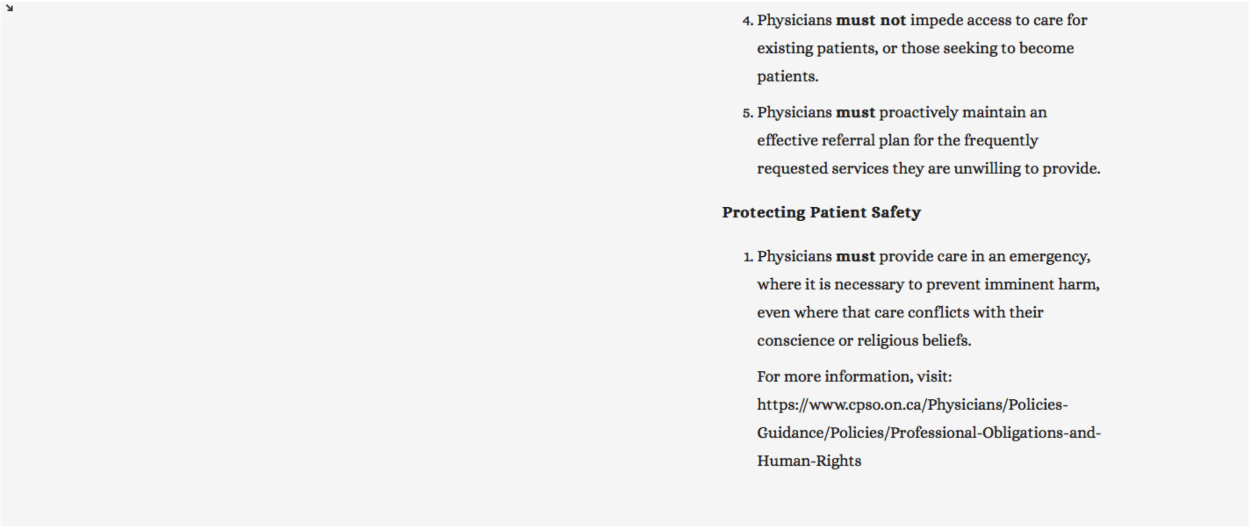
1. Where physicians object to providing certain elements of care for reasons of conscience or religion, they **must** communicate their objection directly and with sensitivity to existing patients, or those seeking to become patients, and inform them that the objection is due to personal and not clinical reasons.
2. In the course of communicating their objection, physicians **must not** express personal moral judgments about the beliefs, lifestyle, identity, or characteristics of existing patients, or those seeking to become patients. This includes not refusing or delaying treatment because the physician believes the patient's own actions have contributed to their condition.
    1. Furthermore, physicians **must not** promote their own religious beliefs when interacting with patients, or those



seeking to become patients, nor attempt to convert them.

Ensuring Access to Care

1. Physicians **must** provide information about all clinical options that may be available or appropriate to meet patients' clinical needs or concerns.
2. Physicians **must not** withhold information about the existence of any procedure or treatment because it conflicts with their conscience or religious beliefs.
3. Where physicians are unwilling to provide certain elements of care for reasons of conscience or religion, they **must** provide the patient with an effective referral.
   1. Physicians **must** provide the effective referral in a timely manner to allow patients to access care.
   2. Physicians **must not** expose patients to adverse clinical outcomes due to a delayed effective referral.
4. Physicians **must not** impede access to care for existing patients, or those seeking to become

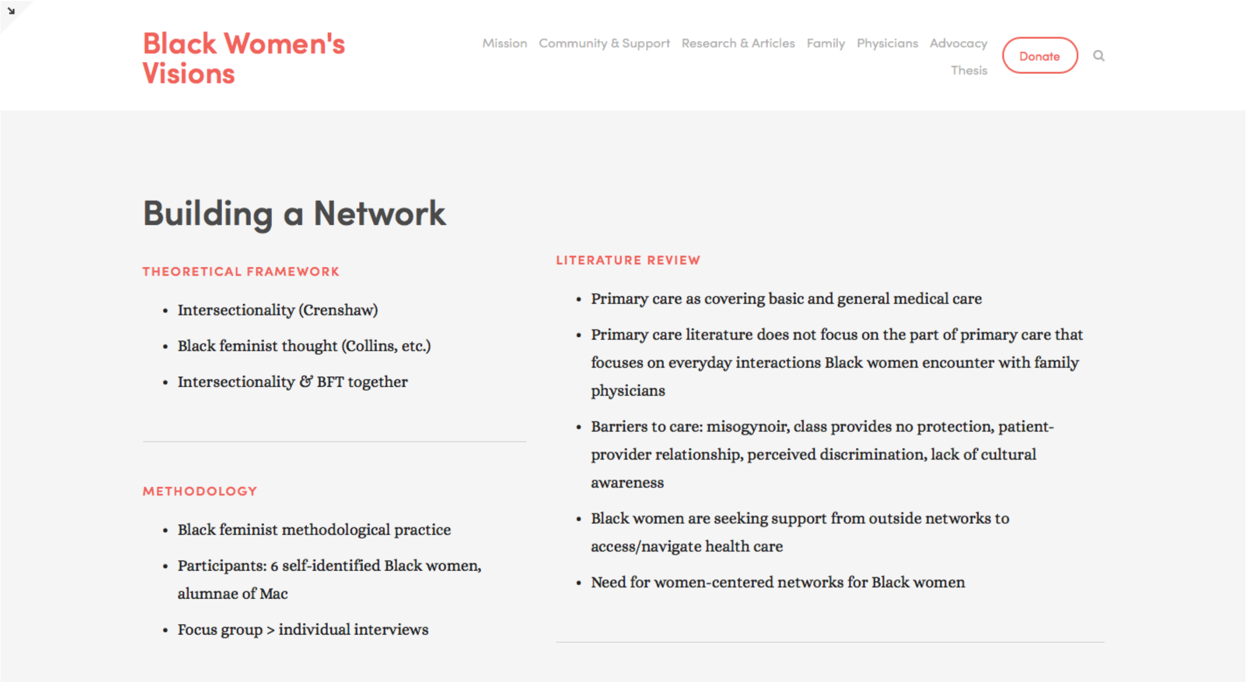


4. Physicians **must not** impede access to care for existing patients, or those seeking to become patients.
5. Physicians **must** proactively maintain an effective referral plan for the frequently requested services they are unwilling to provide.

Protecting Patient Safety

1. Physicians **must** provide care in an emergency, where it is necessary to prevent imminent harm, even where that care conflicts with their conscience or religious beliefs.

   For more information, visit: https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Professional-Obligations-and-Human-Rights



Building a Network

THEORETICAL FRAMEWORK

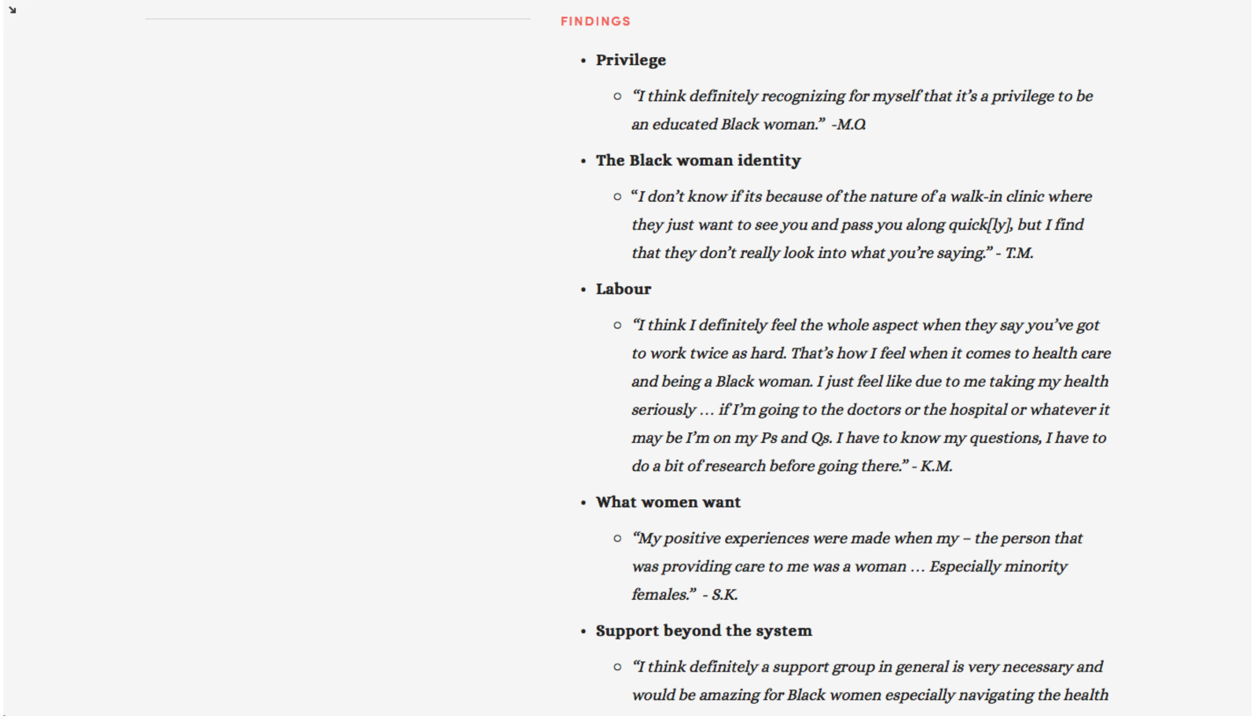
- Intersectionality (Crenshaw)
- Black feminist thought (Collins, etc.)
- Intersectionality & BFT together

METHODOLOGY

- Black feminist methodological practice
- Participants: 6 self-identified Black women, alumnae of Mac
- Focus group > individual interviews

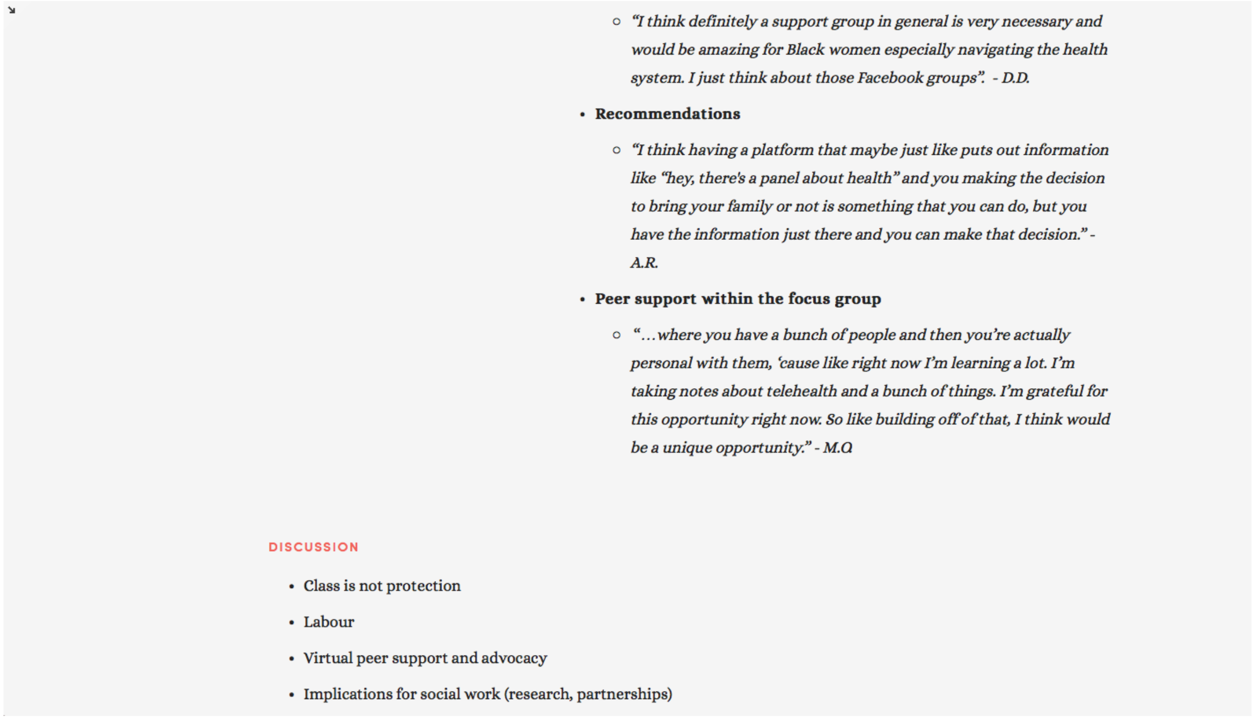
LITERATURE REVIEW

- Primary care as covering basic and general medical care
- Primary care literature does not focus on the part of primary care that focuses on everyday interactions Black women encounter with family physicians
- Barriers to care: misogynoir, class provides no protection, patient-provider relationship, perceived discrimination, lack of cultural awareness
- Black women are seeking support from outside networks to access/navigate health care
- Need for women-centered networks for Black women



FINDINGS

- **Privilege**
  - *"I think definitely recognizing for myself that it's a privilege to be an educated Black woman." -M.O*
- **The Black woman identity**
  - *"I don't know if its because of the nature of a walk-in clinic where they just want to see you and pass you along quick[ly], but I find that they don't really look into what you're saying." - T.M.*
- **Labour**
  - *"I think I definitely feel the whole aspect when they say you've got to work twice as hard. That's how I feel when it comes to health care and being a Black woman. I just feel like due to me taking my health seriously … if I'm going to the doctors or the hospital or whatever it may be I'm on my Ps and Qs. I have to know my questions, I have to do a bit of research before going there." - K.M.*
- **What women want**
  - *"My positive experiences were made when my – the person that was providing care to me was a woman … Especially minority females." - S.K.*
- **Support beyond the system**
  - *"I think definitely a support group in general is very necessary and would be amazing for Black women especially navigating the health*



  - *"I think definitely a support group in general is very necessary and would be amazing for Black women especially navigating the health system. I just think about those Facebook groups". - D.D.*
- **Recommendations**
  - *"I think having a platform that maybe just like puts out information like "hey, there's a panel about health" and you making the decision to bring your family or not is something that you can do, but you have the information just there and you can make that decision." - A.R.*
- **Peer support within the focus group**
  - *"…where you have a bunch of people and then you're actually personal with them, 'cause like right now I'm learning a lot. I'm taking notes about telehealth and a bunch of things. I'm grateful for this opportunity right now. So like building off of that, I think would be a unique opportunity." - M.O*

DISCUSSION

- Class is not protection
- Labour
- Virtual peer support and advocacy
- Implications for social work (research, partnerships)