Understanding and Addressing Racial Disparities in Health Care: Exploring the Information Seeking Behaviours of Racialized Women Managing Chronic Pain

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Abstract

In the area of health information-seeking behaviour (HISB), racialized women require a variety of resources for managing their chronic health conditions, including accessing information from medical professionals. However, this paper explores the ways in which their information sources have been limited due to racial biases or microaggressions from doctors and specialists. A main objective of this study is to establish a framework on which future research can be built. Using Sonnenwald’s (2001) Information Horizons Interview (IHI) methodology, I conducted in-depth interviews with three women living with chronic health conditions, where the participants provided verbal and graphical articulations of their health-related information horizons. The analysis suggests that (1) racialized women rely on the internet, community and medical professionals for information related to managing their conditions; (2) the information received is influenced by racial biases, which devalues the information relevant to care; (3) participants make substantial use of interpersonal resources to make up for this lack of information and; (4) they typically find this information through information grounds and information encountering with other racialized women. Since this research is for participants and not solely about participants, it explores implications and strategies for moving forward in the HISB needs for racialized women in Toronto.

Keywords

racialized women, chronic health conditions, information-seeking behaviour, intersectionality, health inequities, racial disparities, health literacy
INTRODUCTION

The concept of health literacy has been viewed in a limiting way — as a fixed concept that emphasizes functional literacies such as reading, writing and numeracy (Lloyd, Boner & Dawson-Rose, 2014, pp.2010). This paper, however, advocates a holistic approach that focuses on understanding how patients use information to inform their decision-making in relation to the daily management of their chronic health conditions. Consequently, to “become informed... in relation to everyday living and medical settings, participants draw from social and epistemic modalities which represent the spaces of their information landscape” (Lloyd et al., 2014, p. 208). This study seeks to provide insights into the HISB of racialized women in Toronto. To better illustrate HISB through the lens of racialization, I will analyze the ways in which racism impacts the information seeking process. Health inequities can be defined as systematic differences in health among groups of people who have different positions in social hierarchies. These differences are detrimental because they adversely affect the health (construed here as vulnerabilities increasing the likelihood of ill health) of groups already at a disadvantage by virtue of their underlying social positions (Nestel, 2012, p. 181).

This topic was selected because there is no known study with this selected population in a Canadian context. Nestel (2012) states “the lack of intersectional literature on health inequities represents a significant gap in the health equity literature and renders social researchers at risk of producing data that are as ‘misleading as they are incomplete’” (p.14), which extends to HISB literature. As a member of this group, I believe that proximity to these issues reveal important implications for ways to move forward. Additionally, this paper will explore resources such as the Internet, medical professionals and community as imperative social resources that were utilized in the information seeking process.

LITERATURE REVIEW

Health literacy is a socially derived health information practice that connects people to ways of knowing and enables them to draw from a range of information sources to inform their decisions (Lloyd et al., 2014, p.207). Similar to Lloyd, Boner & Dawson-Rose’s (2014) study of patients living with chronic illnesses, this paper asserts that “chronic health conditions enact the whole person into an information landscape where patients draw from information that is also derived from social sources (through interaction with others), not just text based” (p. 211). Therefore, becoming health literate is a situated social practice. Similar to Lloyd et al., (2014), the term “chronic health condition” in this paper refers to chronic pain, chronic illness and disability (p. 208). Lloyd et al (2014) states that chronic conditions are those involving a long course in their development or their symptoms. The diagnosis of a chronic health condition constitutes a significant health event and creates a disruption to the biography of people because it constitutes a rethinking of identity and recasting of knowledges (Loyd, 2014, p. 210).

When the lens of racial disparities in health care is integrated, researchers have identified numerous pathways to health inequities related to racism, including the psychological stress of living in a racist environment, inequitable access to education, mistrust of the health-care system and underused screening programs (Nestel, 2012, pp. 21). This paper seeks to fill the void for racialized women who may not be able to relate to other studies about chronic health conditions because those studies lack social intersectionality, which addresses the ways in which
identity politics informs experiences accessing information. Throughout this paper, I will explore pioneering concepts in information science, which include impoverished information world, small world, information grounds, information encountering, and the berry-picking model, through the lives of racialized women who seek information for managing their chronic health conditions.

RESEARCH METHODS

This study examines the information seeking behaviour of racialized women in Toronto through the theoretical framework of information horizons proposed by Sonnenwald (2001) to understand the implications of racial biases in health care management. The concept of information horizons provides a theoretical framework to examine individuals’ information behaviour, especially in identifying the preferred sources people utilize. Interviews were conducted, and participants were asked to describe several recent information seeking situations for their health care needs. Questions asked include: How do racialized women with chronic health conditions gather information when a symptom arises? Are there instances of racism that impact the information received? Participants were also asked to draw a map of their information horizons in this context (Appendix 1). The maps assisted with visually representing the information resources accessed and which resources were favoured. Each interview lasted approximately thirty minutes and was audio recorded for subsequent verbatim transcription. Synthesizing intersecting themes to develop highly conceptualized meta-themes followed. Voluntary informed consent was obtained from participants prior to data collection. All data was deidentified using pseudonyms. Participants include:

Jackie, 30, Lupus
Natalie, 29, Fibromyalgia, New Daily Persistent Headache
Carole, 55, Fibromyalgia, Crohn’s Disease

Ethical considerations included assessing whether my research would cause more harm than good for a vulnerable population such as racialized women with disabilities (my participants all considered living with chronic pain as a disability that significantly impacted their lives). Furthermore, I was unsure whether to consider my Metis participant a “racialized” woman. Because the Indigenous experience with colonialism and settler violence is unique, I did not want to treat racialized women as a homogenous group. I ultimately resolved this issue by simply asking the participant how she wanted to be identified. She identified as a racialized woman and that resolved my concern. In terms of the sensitivity surrounding disability, I focused my questions on information seeking behaviours and resources as opposed to questions about conditions specifically.

FINDINGS

I selected an inductive thematic analysis because it is a useful method for examining the varied perspectives of research participants through highlighting similarities and differences.
and generating unanticipated insights into themes found within the data set. When seeking information for managing chronic pain, navigating the internet, creating community and accessing medical information from professionals were all overarching themes. The way in which racialization informed this process will be briefly discussed.

Dr. Google: Navigating the Internet

All of my participants had access to the internet at home for their information seeking needs. The most frequently researched topics googled were “depression,” “drug therapy” and “coping strategies.” Only Natalie shared the information she found with her doctor, the other two were opposed. This is likely because health care professionals have little faith in the quality of the information available on the Internet (Corcoran, Haigh, Schug, 2010). Similar to Corcoran et al’s (2010) study of chronic pain patients utilizing the Internet, my study participants did not use the Internet as an alternative information resource to their doctors, but instead as supplementary information. Furthermore, although the retrieved information can be overwhelming, it can also empower patients as participants in their care (Corcoran et al., 2010). Carole states “sometimes the information online is scary, and it can be misleading to your specific issue. You need to be careful.” Despite Carole’s caution over the internet, in Figure 1, she reveals that the Internet is her preferred information source when an information need arises.

Figure 1: Carole lists the Internet as her first preferred resource to seek information when an information need arises about her health (i.e. a new symptom that she is experiencing).

Moreover, the Internet is an information resource that assists with the changing nature of queries, or an evolving search (Bates, 1989). An example of this is when Jackie looked up a symptom that she was experiencing and a pop-up ad with an image of an engagement ring generated. She then googled “Black women dating with chronic pain,” which led her to a Facebook group on the same topic. In the Facebook group, there were certain other resources
mentioned that she wanted to explore. She then refined her query, not only in order to better express her information need, but also because the information need itself had changed (Bates, 1989). Bates refers to this bit-at-a-time retrieval as “berry picking.” Another example of berry picking manifests in Natalie’s tendency to engage in citation searching to access information (Bates, 1989). Evidently, various information searching tactics were used.

Community Matters

Accessing support groups, both in person and online is an important aspect of seeking information amongst participants. Although Carole found her in-hospital support groups helpful, she felt alienated as the only racialized woman. She felt like her experiences with racism in health care would be undermined. Carole states “this is my experience in almost every other area of my life that includes white people. I am always accused of using some mythical ‘race card’ and I didn’t want to make enemies in a group I really need.” This has forced her into an impoverished information world because she cannot access information on how to cope with her illness along the lines of racialization. Chatman (1999) states “a decision to risk exposure about our true problems is often not taken due to a perception that negative consequences outweigh benefits” (p.197). Natalie escapes this position of information poverty by utilizing social media. In her IHI diagram in Figure 2, she illustrates going on Facebook to find groups specifically for racialized women with chronic pain conditions. She considers these groups a safe space where the exchange of information is not anxiety-inducing.

Information from Medical Professionals

All three participants had distinctive experiences with racial biases or implicit microaggressions from medical professionals when seeking information for their care. Jackie shared that an OHIP covered psychotherapist repeatedly asked, “where are you from?” Jackie said during the interview: “I said Toronto and he pressed on and asked me what my country of origin was, assuming it wasn’t Canada. When I eventually said my parents were Trinidadian, he said ‘oh they are very backwards over there.’ I was so pissed. This is the man I am supposed to discuss my trauma with? I never went back.” Because of this racially charged xenophobic comment, Jackie never went back to visit the therapist, therefore eliminating the mental health information component of managing her illness and missing information relevant to her care.

Natalie, who is of Indo-Caribbean descent detailed her experience with her gastroenterologist: “He told me that since I was Black, I didn’t need to worry about a gluten intolerance. I’m not even Black! It goes to shows anyone who wasn’t white just looked the same to him. Also, that information is not true.” In this circumstance, Natalie’s racial identity limited her from accessing an important screening service she needed for information on her condition.
Figure 2: Natalie illustrates her process for accessing support groups on Facebook for racialized women seeking support for chronic pain management. She illustrates accessing the internet first by heading over to Facebook, finding groups for chronic pain and racialized women separately and then ultimately accessing groups that merge both.

DISCUSSION

Kuhlthau’s (2009) uncertainty principle refers to “a cognitive state that commonly causes affective symptoms of anxiety and lack of confidence. Uncertainty and anxiety can be expected in the early stages of the information search process.” The individual eventually gains confidence as knowledge shifts and becomes situated contextually, a phenomenon that was evident amongst all participants as they accessed information relevant to their health. However, there was a notable limitation to this — experiences with racism from medical professionals. This has important implications for health literacy researchers who are seeking to understand the needs of patients accessing information in the health care setting. An intersectional approach that considers identity politics should be expanded on in this area. Evidently, lack of cultural competence, unconscious racial bias, inaccessible screening services and unfounded beliefs in race-based biological differences all produced racial inequities in the delivery of health care, a main information resource for managing health issues amongst my participants (Nestel, 2012, p.7). This revelation prompted me to think about the ways in which racialized women access information for self-care in the face of racism from medical professionals. This topic of interest derived from the interviews, where my participants exemplified how exhausted they can get from racist encounters in the medical field and beyond. Following Chatman’s various explorations of how marginalized populations experience information in connection with everyday need, exploring information resources for self-care among racialized women with an information
science lens is an area that I would like to contribute research to. One example of how Jackie accessed this type of information was through information grounds—a gathering of individuals anywhere and not usually for the purpose of information sharing (Fisher, Durrance, & Hinton, 2004, pp.755). In her case, social gatherings with racialized women served as information grounds for unintentionally exchanging information that related to coping with racism. Although these gatherings did not occur for that purpose, they spontaneously happened, which is also an example of information encountering. Information encountering refers to the serendipitous sharing of information that was not originally being sought (Erdelez, 1997, p. 412). This information was limited because her friends did not have the embodied experience of living with a chronic illness, however. Therefore, it would be beneficial for programs to have groups that encourage discussions about racism in the health field. Chatman’s concept of a “life in the round” refers to a “public form of life in which things are implicitly understood” (Chatman, 1999, p. 212). This concept can be used to explore how people come together to access information and resources on racism as well. At Jackie’s gatherings, no one would be accused of a “using the race card;” it is just known that racism occurs. These instances of sharing information about self-care in a racist society reflect a small world. A small world is a society or world in which members share a common worldview (Chatman, 1996, p. 201). Chatman (1999) notes that within a small world, members decide what is and is not important and which sources can be trusted. Hence, “whereas insiders see their codes of behaviours as normative, routine, and as fitting shared meanings, outsiders to the group cannot relate, because they do not share the same social meanings (p. 80).

METHODOLOGICAL REFLECTIONS

The IHI method is a fascinating way to conduct research because of the various nuances in the interview process. The in-person interviews allowed me to pick up non-verbal information through body language and facial expressions. Additionally, Natalie amiably voiced that the IHI drawing helped her realize that she was more proactive in her health than she previously believed. It was a defining moment of reflection that led to pride in the process of empowering herself with information. She kept a screenshot to remember how far she has come. The interviews were successful; however, the drawing component may not have gone as smoothly if the participants were unknown to me. Reflectively, I did engage in a lot of reassuring because two of my participants felt uncomfortable with having to draw such intimate details of their lives. I believe this reassurance was effective because both knew me personally and trust was established.

CONCLUSION

This holistic approach to understanding chronic health experience acknowledges that other information modalities (social in particular) act as critical sites of knowledge from which to draw information (Lloyd et al., 2014, p. 213). My participants’ racial identities impacted their information horizons and therefore this analysis raises many questions about how we might begin to address the unequal health outcomes faced by racialized women. Participants who experienced explicitly racist remarks from medical professionals engaged in the self-protecting behaviour of never returning to these resources. These incidents have led to them missing
critical information relevant to their care and forced them to inhabit impoverished information worlds for those specific information needs. Nestel (2012) states “there is a consensus amongst researchers that any study of the pathways to health inequities must incorporate a specific focus on racial and/or ethnic group membership in order to devise targeted remedies to this problem” (p.10).

However, racial identities have also empowered my participants to seek out online support groups and build communities that are safe spaces, providing them the opportunity to share their unique experiences to empower others. The interview process itself served as an unexpected form of community building. In their own ways, participants voiced how therapeutic our interviews were. They felt connected to my experiences as a racialized woman living with a chronic illness, which helped remove the usual power dynamics between interviewer and interviewee and instead facilitate a safe space for sharing sensitive information. My role as a researcher who is invested in studying marginalized populations also taps into my desire to engage in diverse forms of information activism as it intersects with identity politics. Recognising the need for more spaces to exchange information for racialized women, I created a WhatsApp group called “You Ok, Sis?” to check in on my participants and share information that we come across for pain management. Other racialized women we meet along the way that want to learn and exchange information about their condition will be added. When racist encounters or microaggressions occur, we can also discuss how best to remedy the encounter and practice self-care in a community-built safe space.

REFERENCES


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**APPENDIX 1 – IHI MAPS FROM ALL STUDY PARTICIPANTS**

Figure 1 - Carol’s IHI Map
Figure 2- Natalie's IHI Map

Figure 3- Jackie's IHI Map