

Endometriosis & the African, Caribbean, Black (ACB) Community in Canada

Mino Care Final Report

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Final Report: SOGC Endometriosis Project

Focus Group Discussion: Endometriosis in the Black Community

Endometriosis, a chronic condition in which tissue similar to the uterine lining grows outside the uterus, affects millions worldwide. However, awareness and understanding of endometriosis remain limited within the Black community. This focus group, consisting of 25 individuals from the Black community, aimed to explore perceptions, experiences, and challenges related to endometriosis, particularly within the Black community. Participants included both patients and caregivers who shared insights into stigmas, barriers to care, and misconceptions surrounding the disease, as well as potential improvements in awareness, diagnosis, and treatment.

Findings

Two primary themes emerged from the discussion:

Lack of Support from Healthcare Providers and Social Circles: Many participants reported feeling unsupported by healthcare providers and their immediate social circles. Due to widespread misunderstanding and dismissal of endometriosis, patients often rely on peer networks for support. While these connections help alleviate isolation, they also underscore the absence of professional guidance and care.

Stigma and Personal Responsibility: Participants expressed that endometriosis patients frequently experience stigma due to the condition's invisible nature, compounded by racial and gender biases. Black women, in particular, face harmful assumptions, such as having a higher pain tolerance or exaggerating their symptoms. This stigma fosters a sense of personal responsibility, pressuring individuals to endure pain and focus on lifestyle changes (e.g., diet and exercise) rather than seek medical help.

Awareness and Public Understanding

When asked about public awareness of endometriosis, participants overwhelmingly highlighted the lack of education and pervasive stigma. Key points included:

Invisible Illness: The severity of endometriosis is often unrecognized because those suffering may appear healthy. Symptoms are frequently dismissed by healthcare providers, leading to delayed diagnoses and inadequate support.

Limited Media Representation: The media underrepresents Black women's experiences with endometriosis, reinforcing the misconception that it primarily affects white women or is merely a 'painful period.'

Misconceptions and Myths: The focus group discussed several prevalent myths and misconceptions that hinder proper diagnosis and treatment:

Pain is Normal: Severe period pain is often dismissed as a natural part of menstruation, leading many to believe endometriosis is just an extreme form of normal cramps. This misconception results in individuals being told they are overreacting or that a hysterectomy is the only solution.

Only Affects Certain Demographics: There is a false belief that endometriosis only affects older women, pregnant women, or those trying to conceive. This narrow view contributes to delayed diagnoses.

Infertility is Inevitable: While infertility can be a symptom, not everyone with endometriosis experiences it. One participant shared their experience of conceiving naturally despite being told they were likely to suffer multiple miscarriages.

Simple Solutions: Patients are often advised to modify their diet or lifestyle as a primary treatment, which rarely provides sufficient relief. This advice undermines the severity and complexity of the condition.

Myths Fuel Stigma: The prevalence of these myths contributes to a broader stigma, making it difficult for individuals to feel comfortable discussing their symptoms and seeking help.

Managing Pain and Emotional Well-Being

Endometriosis is marked by chronic pain that affects both physical and emotional well-being. Participants shared various coping strategies and discussed the emotional toll of living with the condition:

- **Social Support and Distraction:** A key theme was the reliance on family and community support. Patients expressed that staying connected with loved ones helped mitigate feelings of isolation, and often, just having someone listen to their experiences was a crucial form of support.
- **Physical and Emotional Exhaustion:** Chronic pain led many participants to experience anxiety, stress, depression, and emotional exhaustion. The need to balance the daily struggles of endometriosis with external expectations can be overwhelming.
- **Heat Therapy and Pain Management:** Common methods of managing pain included the use of heat therapy, such as heating pads or warm baths. Many also turned to painkillers, pelvic floor physiotherapy, and hormonal therapies to manage their symptoms.

- *“Don’t let anybody tell you you need to endure the pain”*
- **Mental Health:** The psychological impact of the disease was significant. Participants noted that living with the emotional strain of a chronic illness, especially one with so many misconceptions, often leads to increased anxiety and depression.

Cultural Practices and Beliefs in the Black Community

The discussion also explored how certain cultural practices might help or hinder a person’s experience with endometriosis:

- **Traditional Medicine:** In some African cultures, herbal remedies and spiritual ceremonies are often used to manage menstrual issues, which can complement or conflict with Western medical treatments.
- **Social Stigma Around Reproductive Health:** The Black community’s emphasis on fertility and childbearing can create additional pressure for individuals experiencing infertility due to endometriosis. This can lead to feelings of shame and isolation.
- **Resilience and Strong Family Support:** On a positive note, many participants highlighted the strength of the Black community’s support system.
 - *“Strong family and community support helped me feel less isolated”*

Barriers to Treatment

The participants noted several barriers in accessing effective treatment for endometriosis:

- **Stigma and Financial Constraints:** The stigma surrounding endometriosis, combined with financial barriers, makes it difficult for many patients to seek and afford treatment.
- **Medical Bias and Discrimination:** Participants discussed the medical bias that Black patients often face, including the dismissal of their pain and delayed treatment. There is also a perception that Black patients are expected to endure more pain due to cultural stereotypes of resilience, which can result in poor treatment outcomes.
 - *“They may not fully understand how systemic racism affects the healthcare experiences of some black individuals including delayed diagnosis and inadequate treatment”*
 - *“Many black individuals have mistrust issues”*



- **Cultural Stigma:** The stigma around reproductive health, especially in Black communities, makes it hard for individuals to openly discuss their symptoms and seek care. This lack of discussion can further delay diagnosis.

Recommendations for Change

To improve support and care for Black individuals with endometriosis in Canada, the focus group proposed several key changes:

1. **Healthcare Provider Training:** Ongoing cultural responsiveness training for healthcare professionals to enhance understanding of how endometriosis presents in Black patients. Encouraging active listening and communication can foster stronger patient-provider relationships.
2. **Increased Awareness and Education:** Expanding public education efforts, both online and offline, to increase awareness of endometriosis within the Black community.
3. **Community Engagement:** Creating more support groups and online forums to reduce isolation and provide valuable resources.
4. **Affordable and Accessible Healthcare:** Efforts should be made to improve access to affordable healthcare, with a focus on reducing financial barriers to treatments.
5. **Research and Policy Advocacy:** Increasing research on endometriosis in Black women and advocating for policies that promote culturally safe, patient-centered care.

Evaluation of Endometriosis Resources

Mino Care conducted an analysis of over 187 endometriosis-related resources, identifying significant gaps in accessibility, cultural sensitivity, and relevance to underserved populations, particularly Black communities. Key findings included:

Limited Availability of Canadian Resources: The majority of available materials were international (e.g., U.S., U.K., Australia), with a scarcity of Canadian-specific information. This limits access to relevant, local resources.

Lack of Focus on the Black Community: Existing materials fail to address how race and cultural context impact diagnosis, treatment, and emotional well-being, leaving Black Canadians without tailored support.

Cultural Sensitivity Gaps: Resources often overlook the unique challenges Black individuals face, such as cultural stigma and healthcare discrimination, making them less relatable and effective.

Participant Feedback on Adapted Resources

Participants reviewed an adapted endometriosis fact sheet for accuracy, cultural relevance, and effectiveness. Participants were provided with the adapted resource and asked to complete an evaluation. The responses to the five Likert scale questions were overwhelmingly positive. Feedback was overwhelmingly positive, with most agreeing that the resource provided accurate medical information while acknowledging systemic biases and promoting cultural safety. This indicates that the resource successfully met the expectations of the participants in terms of reflecting accurate medical information while being mindful of cultural sensitivities. When asked whether they felt more empowered and informed after reading the fact sheet, participants responded with strong agreement.

When asked for suggestions on how to improve the adapted endometriosis resource to better address the needs of Black individuals, participants noted both macro and micro-level improvements. On a macro level, one participant emphasized the need for increased awareness through seminars, webinars, and presentations, stating that many people are unaware of the condition. On a micro-level, another participant highlighted the importance of individual strategies, such as using techniques to release “feel-good chemicals” to manage pain and relaxing pelvic floor muscles to alleviate symptoms. These suggestions reflect a balanced approach emphasizing both broader education efforts and personal empowerment in managing endometriosis.

Conclusion

Both the focus group and resource evaluation highlight significant gaps in support for Black individuals with endometriosis. Stigma, lack of healthcare support, and misinformation contribute to these challenges, reinforcing reliance on family and community for emotional support. A participant noted, “*Googling information makes it worse and increases fear and stigma,*” emphasizing the harmful impact of misinformation.

The limited availability of Canadian-specific, culturally sensitive resources further compounds the issue. To address these disparities, healthcare providers must improve communication and training, research must expand, and educational materials must become more inclusive. By taking these steps, we can improve the experiences of Black individuals living with endometriosis and ensure they receive the care they deserve.