

Revealing The Voices of Women Living with IBD

Research Team

Sarah Sebastian (BSW Ryerson University)

Jordyn Perreault-Laird BSW (Ryerson University), MSW (McMaster University)

Susan Silver, Associate Professor, School of Social Work, Ryerson University



Abstract

The purpose of this exploratory study is to center the voices of women who are living with inflammatory bowel disease (IBD) in order to understand their lived experiences and the kinds of support and resources they most value. Our review of the literature has indicated that studies which reveal the personal, lived, qualitative experiences of women with IBD are scarce. Instead, the existing body of research tends to be highly medicalized and expert- driven. In this study we constructed a sample of 20 YouTube videos posted by women living with Crohn's Disease and Ulcerative Colitis, who openly shared their experiences of living with the disease. Using phenomenology, coupled with an intersectional lens, we explored how living with IBD was informed by gender, race, class and age. We hope to publish this exploratory work as a way to begin to address the gap in our understanding of the lived experiences of IBD.

The Research

Research Goals

There is a lack of research in which IBD patients themselves, specifically women, describe their experiences, and their unique way of living with IBD. Thus, our goal is to center the voices of women living with IBD. We also hope to create better resources and deepen our understanding of the barriers women encounter to receiving effective care.

Methodology

In this study we use a phenomenological methodology which is coupled with an intersectional lens. This will assist in revealing the intersectional experiences of gender, race, class and age. Additionally, we are interested in the experiences that women have in the health care system and with IBD including the length since diagnosis, medications and surgeries.

The Process

- 1) Conducted a comprehensive literature review of chronic illness, IBD, illness narratives, and patient outcomes research.
- 2) Search keywords on YouTube consisted of “My Story of IBD,” “Living with IBD,” and “IBD story.”
- 3) 114 YouTube videos were reviewed, specifically searching for videos posted personally by the women themselves within the last **5 years**, between the ages 15-45 years old and who are living with Crohn’s or Ulcerative Colitis.
- 4) A diverse and purposive sample of **20** videos were selected for further analysis.

Next Steps

The videos make visible the complexity of living with IBD, as the women openly share their feelings, experiences, and the knowledge they gained as they navigate the medical system and their everyday lives. We are continuing our work with the videos and plan to publish this exploratory study.

