

Patients views of the unmet needs of living with Myalgic Encephalomyelitis in British Columbia

Lana LeBlanc¹, MPH; Hilary Robertson¹, MScHA, PhD; Kati Debelic¹, RN, BScN; Luis Nacul², MD, PhD; E. N. Prestley³, BA; T. Boulter², BA
¹ME/FM Society of BC (BC, Canada) ²Complex Chronic Diseases Program (BC, Canada) ³Women's Health Research Institute (BC, Canada)

Background

Understanding the explicit needs of British Columbians living with ME is critical to informing research that improves patient outcomes.

This community led project was designed as a catalyst for a provincial needs assessment through the identification of key stakeholders and piloting of methods.

Objective

1. Test feasibility of conducting a provincial needs assessment
2. Identify and engage health sector stakeholders critical to mobilization of research outputs
3. Collect preliminary data regarding barriers and facilitators to health service provision and access.

Methods

- People living with ME were identified as a key stakeholder group & recruited from the ME/FM Society of BC to participate in individual interviews and focus groups.
- Semi-structured interview and focus group guides were developed, and thematic analysis of content was conducted.
- Community members trained in qualitative research methods led the data collection and analysis.

Results

- The invitation for patient engagement resulted in 55 responses. Selection of participants aimed to balance age, sex, geographic location, and severity.
- 25 patients participated: 8 one-to-one interviews and 17 participants in 4 focus groups.
- Patients participated virtually without any travel required, thus allowing more severe patients and broader geographic representation to occur.

Conclusions

The patient interviews highlighted four key themes to the ME experience in BC. Patients expressed gratefulness to participate overall, and also from their own homes. This pilot suggests that online/virtual participation seems favourable for the more moderate to severely affected ME patient community as it reduces the exertion requirements of travel and more public participation.

Limitations

- This project engaged with 25 patients, yet estimates indicates there could be an 77,000 individuals with ME in BC. Recruitment was conducted through the ME/FM Society and therefore not random.
- Findings are limited to this group and cannot be extrapolated across all those living with ME in BC.
- A larger, more expansive project would allow for greater depth of inquiry, broader participation and clarity of conclusions.

Key Themes



Social Isolation

- Profound isolation is experienced by ME patients
- Loss of ability to work, to parent, to socialize with family/friends impacts social connections
- Navigating for medical support is often done alone

"ME took away every single thing. Every single construct I was as a human being."



Supports needed for ME

- Living with ME differs if family/partner support is available
- Patients describe inaccessible and/or scare healthcare system supports, with unclear care pathways
- Basic living and financial support needs are often not met

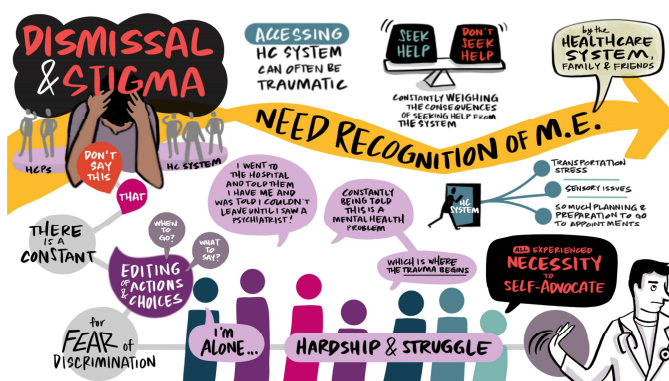
"If I have to cook my own food. I am too tired to eat."



Diagnosis Challenges

- Patients recalled lengthy journeys to seek diagnosis, often taking years.
- Diagnosis, while validating, is not met with awareness and support across the healthcare system
- Knowledge and training about ME in healthcare professionals is lacking

"If your doctor doesn't believe you, you spend so much time, energy and frustration trying to find help."



Dismissal and Stigma

- Dismissal and stigmatization is persistent and consistent patient experience.
- Experiences of dismissal impacts future healthcare interactions
- Patients continually must self-advocate

"When you say you have ME to a doctor they make a disparaging comment or they look at you blankly."