M.E. IN BC:
HOW THE HEALTHCARE SYSTEM FOR M.E. IMPACTS CLINICIANS AND PATIENTS

A preliminary project examining the unmet needs of British Columbians living with Myalgic Encephalomyelitis (ME)

"ME took away every single thing. Every single construct that I was as a human being". *– BC Patient*

"I feel extremely sorry for them because BC has almost nothing for them."
– *BC Clinician*

The ME/FM Society of BC partnered with the WHRI (BC Women's) to receive a Convene Grant from the Vancouver Foundation to complete this work. Vancouver Foundation is dedicated to creating healthy, vibrant and livable communities across BC. Since 1943, our donors have created 1,800 endowment funds and together we have distributed more than $1 billion to charities. From arts and culture to the environment, health and social development, education, medical research and more, we exist to make meaningful and lasting improvements to communities in BC.

ME|FM Society of BC
Myalgic Encephalomyelitis & Fibromyalgia

WOMEN'S HEALTH RESEARCH INSTITUTE AT BC WOMEN'S

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Overview

This patient led community inquiry project was conducted through a partnership between the ME/FM Society of BC, the Complex Chronic Diseases Program at BC Women's Hospital + Health Centre, and the Women's Health Research Institute. The project was funded by the Vancouver Foundation through the Convene competition.

Understanding the explicit needs of British Columbians living with Myalgic Encephalomyelitis (ME) is critical to informing research that improves patient health outcomes. Robust evidence ensures health and social services are designed and delivered effectively and appropriately to the ME community, which includes patients, clinicians, and health care decision makers.

The primary focus of this project was to plan for a health needs assessment on ME/CFS in the province of British Columbia. A secondary objective was to conduct a preliminary assessment of the needs/ barriers to service provision and challenges in health service delivery to ME patients across British Columbia (BC).

Eight one on one patient interviews, four patient focus groups and one online clinician/health professional survey were conducted. In total, 25 patients (8 individual interviews and 17 participants in 4 four focus groups) and 173 clinicians participated, with representation from all regional BC health authorities. The eight individual patient interviews informed the themes used to further the exploration through four thematically oriented focus groups. Following these the services of a graphic recording artist was employed to capture and translate themes into a graphic/visual format. The ME population is varied and with varying capacity for methods of communication and understanding, it was agreed that both written and graphic presentations would support dissemination of the project material. Following the focus groups, an online survey was distributed through both organizations' social and communication networks to engage clinicians and health care decision makers/stakeholders. Survey questions related to clinicians' knowledge, experience and assessment of service provision to ME patients in BC.

The patient interviews highlighted four key themes to the ME experience in BC:

- Social isolation, loss of identity and the need for emotional support
- Supports for disease management and how to live with ME
- Challenges to diagnosis
- Stigma in the healthcare system

The clinician survey identified parallel challenges noting the need for:

- Increased awareness of ME within the clinical community
- Improved clinical resources (e.g. diagnosis pathways and clinical guidelines)
- Improved community referral resources including more options for patients
- Improved empathy for the patient experience/lack of options for patients

Overall, key findings presented from this project have been defined:

1. Patients' experiences of living with ME is dire, alarming, and urgent
2. Patients are concerned with the medical system's poor awareness of ME
3. Both patients and clinicians acknowledge a paucity of available clinical care resources
4. Clinicians expressed a desire for improved education for ME care

Undertaking a community-based approach in building a province wide needs assessment is critical for targeted strategies to inform practitioners, policy makers, and patients and their support teams. This project report provides a clearer picture of unmet needs and future directions established by ME patients. This application of the community-based approach and working with 'patients as partners' aligns with the national viewpoint of ME research efforts and ideally, will allow others beyond BC to learn from our gained insights. Through patient focus inquiry exploring facilitators and barriers to health services, it is hoped that future research, policy and practice can be designed to serve both patients and the health system in an effective and economical manner.

Acknowledgements

We gratefully acknowledge the funding support from the Vancouver Foundation. Convene grants from the Vancouver Foundation support project teams to gather information, meet with key stakeholders to learn more about the complex issue, and to articulate the research question, methodology, and partnership. This type of support is incredibly needed in exploring and bringing forward complex patients' experiences such as those with ME in BC.

To those with ME in BC, you responded to our invitation of participation with willingness, candour and emotion. Your impressive determination to improve the patient experience in BC is much appreciated. We know that your participation was not without planning or consequence. We are grateful for your contribution.

To the clinicians and other healthcare professionals who provided time and thought, your contributions mirrored the experience of the patients. We sincerely appreciate your thoughtful contributions and reflections related to caring for ME patients in BC.

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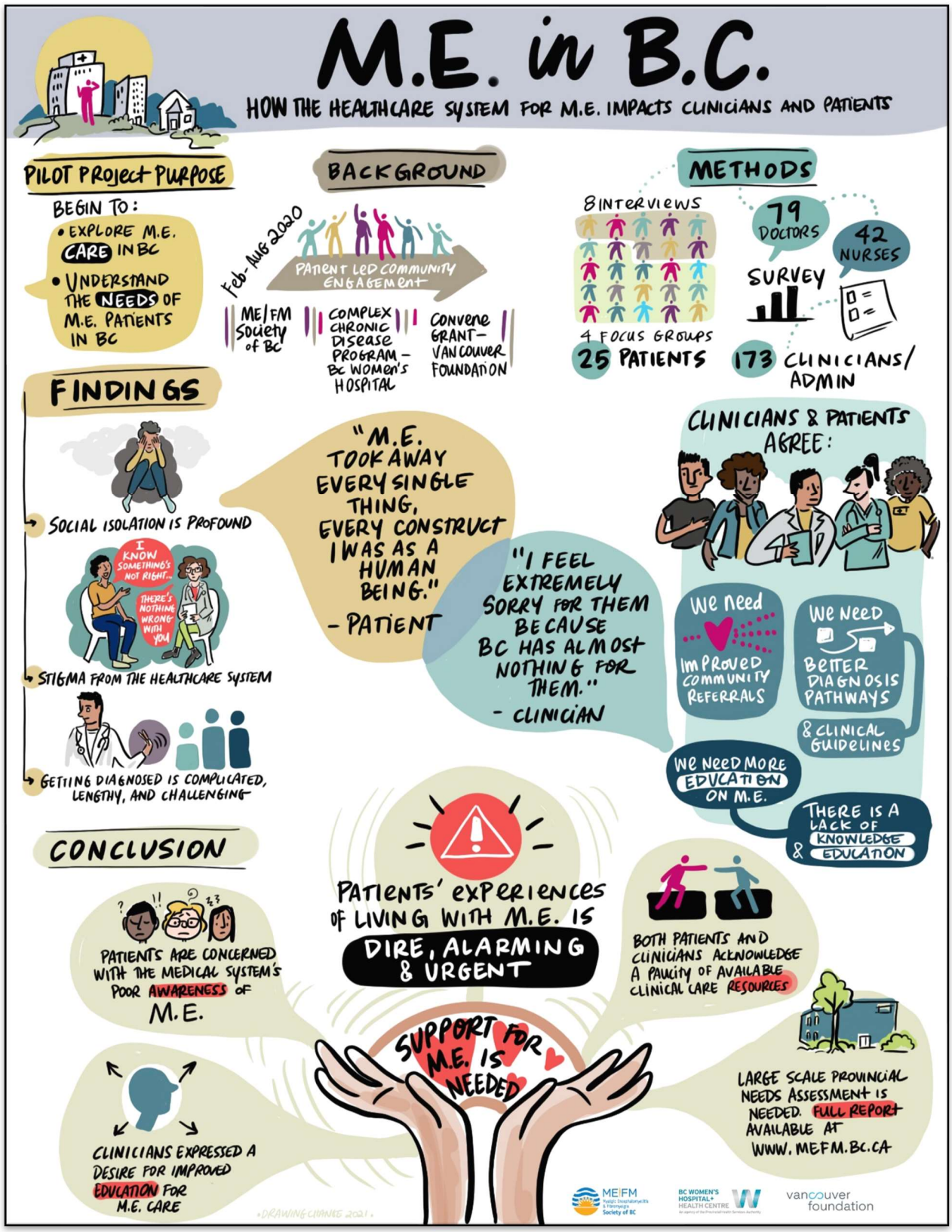
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ME/FM Society of BC
BC WOMEN'S HOSPITAL + HEALTH CENTRE
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DRAWING CHANGE 2021

Introduction

"I am a living piece of evidence that people can go from living normal lives to really not living at all in a matter of moments". Patient

It is estimated as many as 77,000 British Columbians live with Myalgic Encephalomyelitis (ME)[1]. ME is a systemic inflammatory condition, usually with an acute infectious onset, characterized by a marked reduction in functioning and a severe worsening of symptoms after even minimal exertion. ME can have mild, moderate or severe impact on daily functioning. Mild patients may be able to do some typical activities of daily living with some difficulty yet needing periodic rest, whereas severe patients are typically housebound and likely predominantly or continually bedbound and dependant for most if not all, activities of daily living. It is a devastating multi-system disease that causes dysfunction of the neurological, immune, endocrine and energy metabolism systems. The most typical symptoms include: cognitive impairment, muscle pain and headaches, severe sleep disturbances, sensitivity to light/sound/touch/smell, muscle weakness, digestive issues, difficulty to tolerate upright positions, difficulty breathing, body temperature fluctuations, and post exertional malaise (PEM) which is the hallmark symptom of the illness. PEM results whenever a person with ME overexerts (which could be as little as going to the bathroom or talking for too long), involves the delayed onset of worsening of most symptoms, and which can last hours, days, weeks or even months.

For patients with ME, the burden of disease is high (compared to most other chronic disease categories) with significant social, medical and economic costs because of its disabling and chronic nature, delays in diagnosis and lack of approved treatments. The common misconception in health care is that ME is psychologically induced which then contributes to a lack of recognition of the biological nature of the disease and the severity of its effects. These misconceptions have in turn created limitations for the health system to diagnose, treat or support ME patients. The devastating impact of the disease and the problematic health and social care provision on the lives of ME patients cannot be overstated, as it affects their lives medically, financially, socially and emotionally.

Given the prevalence and impact of the disease, and the permanence of the disability it imposes, the economic impacts include: health care costs for a large group of patients with a long-standing disease for which no curative treatment is available, and a loss of income. Current primary health care services are inefficient at supporting ME patients due to limited physician education and knowledge on ME often resulting in multiple unfruitful doctor visits over months or years before receiving a proper diagnosis. Further there is a lack of research evidence in this field due to a lack of funding not enough specialized ME researchers.

This project - designed as a preliminary inquiry in preparation for a larger, province wide study, began to examine ME patient and health services needs within the provincial context. Additionally, this project was undertaken with a view to plan and enable a full health needs assessment, which will ultimately generate evidence to inform health policy decision making in British Columbia. To date, a comprehensive needs assessment of this type had not been completed in British Columbia, nor elsewhere in Canada. Such an undertaking, while focused on ME patients in BC, is intended to support, inform and improve

[1] ME/FM Society of BC, (2018). The unmet health care needs of British Columbians living with Myalgic encephalomyelitis. https://drive.google.com/file/d/1qy9jzg_Uvv45EwkOJWLOM9fS-v45sxlp/view

care for ME patients in Canada and internationally. While focused on ME patients in BC, this inquiry – as the first of its kind in a Canadian context. This initial project has the potential to be both empowering and necessary to improve the lives of those with ME and to guide development of a robust, multiyear, research study.

Timeline

The Convene grant application was submitted December 31, 2019 and approved January 30, 2020. The project period was from February 3, 2020 – September 30th, 2020.

Partnership

The two partners, ME/FM Society of BC and Complex Chronic Diseases Program (CCDP) share a provincial focus in supporting ME patients in British Columbia:

- The ME/FM Society of BC is a provincial Society with a core value to educate and support patients and their caregivers as they negotiate the journey with ME. The ME/FM Society members were both patients and caregivers within the population of interest.
- The BC Women's Hospital + Health Centre's Complex Chronic Diseases Program is a provincial referral centre that aims to provide comprehensive and evidence-based care to adults with complex chronic diseases, including Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia and Alternatively Diagnosed Chronic Lyme Syndrome. The Program participates in clinical care, education/knowledge transfer and quality improvement/research via the Women's Health Research Institute.

Conducting a preliminary provincially focused needs assessment was a synergistic partnership representing community members, clinicians and researchers. Collectively this partnership has a strong interest to understand the impact of ME in British Columbia, the needs of those with ME, their families, and health/other services, something we aim to fully achieve through a formal needs assessment, which this preliminary work facilitates the nature of the partnership between the patient community (Society) and a clinical research entity (CCDP) offered solid underpinnings of a participatory research approach.

Purpose

This project examined British Columbians living with a disabling chronic illness, Myalgic Encephalomyelitis (ME) and was designed to initiate a process of better understand ME patients' health and social service needs. The project identified key stakeholders, data sources and methodology appropriate to this patient population. It is intended that this project will serve to inform a larger project in the future with a comprehensive assessment of the needs of people with ME.

This report presents a justification for a provincial needs assessment. The diversity of participation in this project allowed us to: 1) identify specific priorities to examine, 2) test the feasibility of mechanics and engagement with this particular patient and stakeholder population, 3) mobilize stakeholder groups for further research, and 4) start planning for the methods and logistics of a full needs assessment. A Road Map for the Needs Assessment is presented towards the end of this report.

Methods

Data collection occurred via 1:1 interviews, focus groups and an online survey. The interviews aimed to identify barriers and facilitators to access care in BC. The focus groups aimed to build on the emerging themes from the interviews. The survey aimed to reach out to various clinical stakeholder groups to understand their professional view related to health service delivery to ME patients. The primary stakeholder engagement goal was patients, as they are typically underrepresented in research. However, engaging with a broad clinician stakeholder group was also an important avenue to begin collecting feedback from. All interviews and focus groups were jointly conducted by the ME Society Lead Investigator, Hilary Robertson and the ME Society Research Coordinator, Lana LeBlanc (peer research team). The third member of the ME Society team, Kati Debelic, served as a ME peer observer in the focus group sessions.

Patient Interviews

Patient participants were recruited through the ME/FM Society of BC Facebook page and member email list. A patient invitation letter was used and interested respondents completed an online survey (Google forms).

One pilot interview and seven individual one-on-one interviews with ME patients were conducted. Caregivers were invited to be included to support patient participation; one spouse was present in an interview. Participants were selected for an interview based on achieving diversity in demographic (age, gender), illness severity (moderate or severe) and geographic locations (rural and urban, at least 3 different locations) across BC.

A semi-structured interview guide was used. The pilot interview offered improvement to the consent process and invoked that pairing the peer research team (rather than individually conducting interviews) would offer more support in administering the interview, as well as debrief and reflexivity practice.

Interviews were co-conducted by a pair of peer researchers. The peer researchers have lived experience with ME and are trained in aspects of qualitative research. Interviews were hosted on an online video conferencing platform and recorded on a separate device. Informed consent was obtained by email and again confirmed by verbal consent at the beginning of the interview. Interviews were transcribed by a subcontractor. Participants were offered a small honorarium issued from the MEFM Society of BC.

Patient Focus groups

Initially, a World Café (WC) hosted in Vancouver, BC was proposed. The intention of this activity was to recruit participation from four ME stakeholder groups (patients, clinicians, researchers, decision maker/managers). This partial day activity was intended to bring forward discussion topic areas by groups, and contribute to a WC summation at closing. A graphic recording artist was planned to document the day. The increased public safety requirements of COVID-19 necessitated the cancelation of the WC activity (*Team decision, March 12, 2020*). The team consulted with other academics skilled at performing online/virtual world cafes regarding online digital options. The project shifted to hosting four focus groups with patients, and summary graphic recording sessions with the peer research team.

Focus group participants were invited from the pool of patients initially recruited as potential interview participants (i.e., from the ME/FM Society of BC mailing list). Four thematic topics were listed on four separate days. Participants could indicate ranked interest in the topics and/or dates of preference. The four focus groups were hosted using an online video-conferencing platform and recorded on a separate device. A focus group welcome script was developed to outline: 1) roles of the research team, 2) mechanics of the online platform technology, and 3) goals of the session. Confidentiality guidelines were affirmed. Verbal consent was obtained. Focus group participants were sent a small honorarium from the MEFM Society of BC. Focus groups were recorded but not transcribed but the two peer researchers collated notes and observations.

Clinician Survey

An online survey was developed by the Project Team and was aimed at testing the outreach to various clinicians, physicians and healthcare administrators in B.C. The survey was short, twelve questions, and taking five minutes to complete. Google forms were used. Respondents did not have access to cumulative responses. Data was exported from the form by peer researchers and stored on secure servers. A survey recruitment plan was developed to include using both project partners' existing outreach methods via social media and through BC Women's Hospital + Centre established employee communication. New contacts were sought via various physician and clinician agencies in the province. Communication contacts were searched to ask for invitation distribution support, and twitter handles were researched. The team developed a tracking document for each member to continue to report additional contacts made during this snowball recruitment approach for future engagement.

Data Security

All data collected throughout this project has been stored on password protected files managed by the peer research team. All data transcribed to the online software used for data analysis (Tagette) was de-identified. The online survey did not collect personal identifiers except where participants opted into a random draw for a gift card. This data was kept separately from the questionnaire responses. All data will be stored until the completion of the project on computer password protected files and a backup USB kept in a locked cabinet in the ME Society Lead Researcher home office. Data is only accessible to the project team. Data will be destroyed when no longer needed, to a maximum of 5 years (August 2025).

Analysis Approach

Online qualitative software (www.taguette.com) was used for coding the qualitative data from the transcribed interviews. A grounded theory approach was used. After initially coding a sample of the transcripts independently, two peer researchers noted and discussed preliminary themes. Any differences were resolved, and duplications were eliminated. Final coding was exported into a thematic table where key themes were discussed and informed the focus group topics. A debrief occurred after each interview and focus group where initial observations were highlighted. Peer researchers made independent field notes from the focus groups and collectively discussed and reviewed further developed themes. Peer researcher bias and reflexivity was discussed amid the analysis process.

The clinician survey was predominately close ended questions. The content of the two open ended questions were reviewed, with common responses grouped thematically.

A graphic artist was contracted to develop visual graphics based on themes emerging from patient sessions, as well as a summative graphics displaying key aspects of the overall project (e.g., project aims, methods, themes). Additional graphics of patient and clinician quotes were developed to be used as social media tools in future project dissemination efforts.

Patient Interviews

The invitation for patient engagement in interviews resulted in 55 responses (1 was removed in duplication, 1 removed for self-disclosure of not having an ME diagnosis from a physician). The responses did not capture the invitation contact point, however a staggered release of invitation first to the MEFM Society of BC Facebook page and a day later to the ME Society email list resulted in approximately half of the responses coming in first from the social media outlet).

Participants self-reported demographic information and disease severity. Both the invitation to participate and the consent form indicated that a diagnosis of ME or CFS from a doctor was necessary. This was not confirmed in medical records. One pilot interviewee and seven participants were interviewed. Participants represented individuals living in Fraser Health (urban and rural), Interior Health (urban), Northern Health (Rural), Vancouver Island (urban and rural), and Vancouver Coastal Health (urban). Participants must have been over 18 years of age. Participation represented the following age groups: one patient between the ages of 25-34 years, one patient between 35- 44, years, two between 45-54 years, one between 55-64, and two over 65 years old. Self-reported disease severity ranged from moderate to severe, however, during the course of interviews the disclosure of the limitations to daily life, symptom difficulty, and inability to leave the home/bed would suggest most interviewees were more severe than initially identified.

Patient Focus groups

From the initial 55 responses, the above 8 interview participants were removed from the contact list leaving 47 possible focus group invitees. Six respondents didn't leave or submit a complete email listed and could not be contacted. Therefore, the recruitment for focus group participation was emailed to 41 potential patients. Nineteen patients indicated interest in the focus group. Selection to the focus groups aimed at balancing demographic (age, sex, geographic location).

Seventeen patients participated in four focus groups as follows: group A (n=5), group B (n= 5), group C (n=4), group D (n=3). Two additional participants recruited for group D did not participate on the day for unknown reasons. Participation represented the following age groups: one patient between the ages of 25-34 years, three patients between 35- 44 years, four between 45-54 years, seven between 55-64, and two over 65 years old.

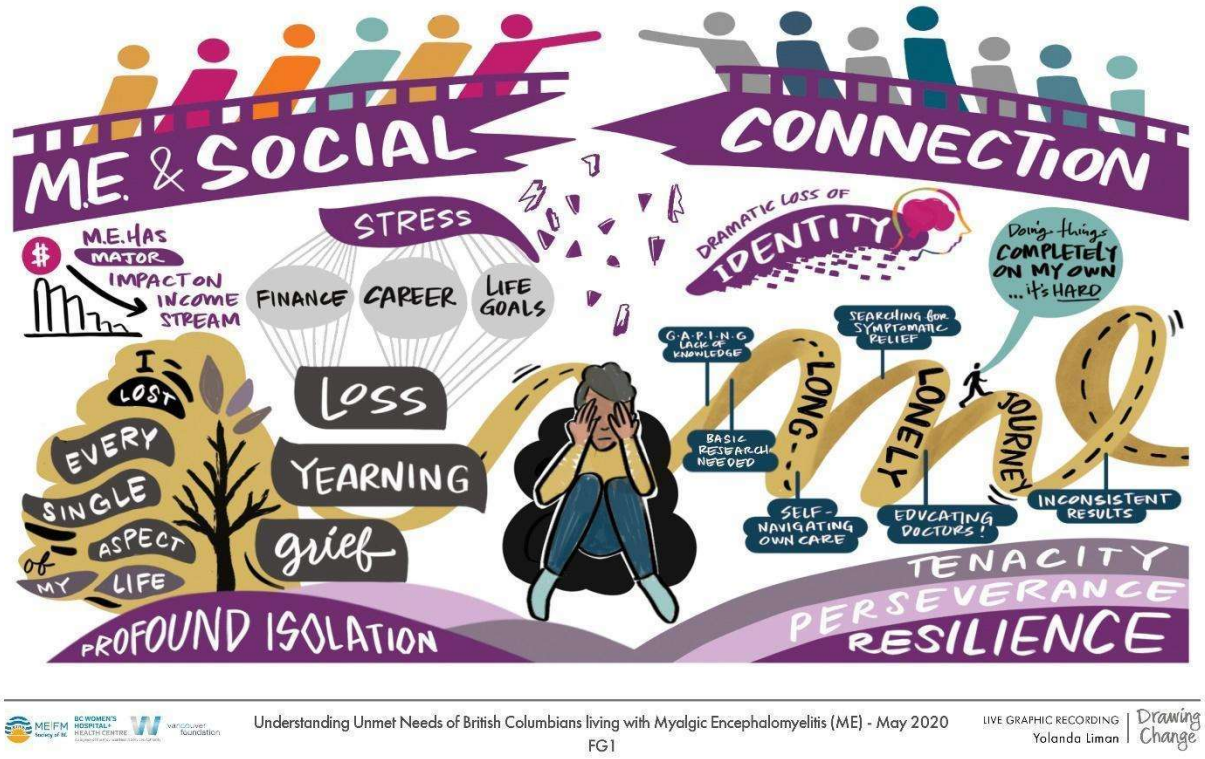
Clinician Survey

A total of 173 responses were collected. Types of clinicians included Family Physicians (53), Specialist Physicians (26), Registered Nurses (39) and Nurse Practitioners (3), Allied health Practitioners (26) Pharmacists (7) and Administrators/Program Managers (9). Ten respondents didn't indicate a profession. Clinician respondents indicated their practices were located throughout BC, with regional representation as follows: Vancouver Coastal (56), Fraser Health (27), Vancouver Island Health (20), Interior Health (14), and Northern Health (8). The Provincial Health Services Authority was indicated by the remaining (40).

Summary of Findings

Patient Themes

Social isolation, loss of identity and need for emotional support



A persistent theme from patients was social isolation while living with ME. Patients described their illness resulting in a loss of prior life and vitality. Most patients discussed aspects of grief and sadness, but not depression or a depressive state; more as a yearning to live life more fully and the challenges of ongoing isolation. Patients described how their illness kept them from being able to engage socially. The majority of patients interviewed discussed how their ME resulted in being too unwell to work, furthering the loss of professional social interaction. The few that did work either did quite minimally from home, or indicated that their part-time work *"left little energy for anything else"*.

Some patients described how carefully they would have to manage a single visitor to their home. Due to lack of unpredictable energy, many patients spoke of having to decline attending family events, unable to handle the stimulus of getting together and/or travel to attend a social activity.

> *"I was thinking people come to visit and you'll pull yourself together for that hour. And then you collapse for a couple of days. And they leave and they say she looks good. And they don't know that I've collapsed for a couple of hours-- or a couple of days after from that hour that they visited. Or if I go to visit my mother, at her nearby retirement home, and it takes me at least two weeks to begin to be able to do anything after visiting her."*

The loss of ability to be with people is profound. Patients without immediate partner or family support, experienced profound social isolation. Patients who had a partner in the home expressed an added loss of adult connection and relationship. Those patients who had children in the home indicated the loss of the parenting capacity and decreased interaction with their children. Many described how they would need to rest from nuclear family interactions in other rooms, and plan for afterschool times so that any possible amount of quality time could be achieved:

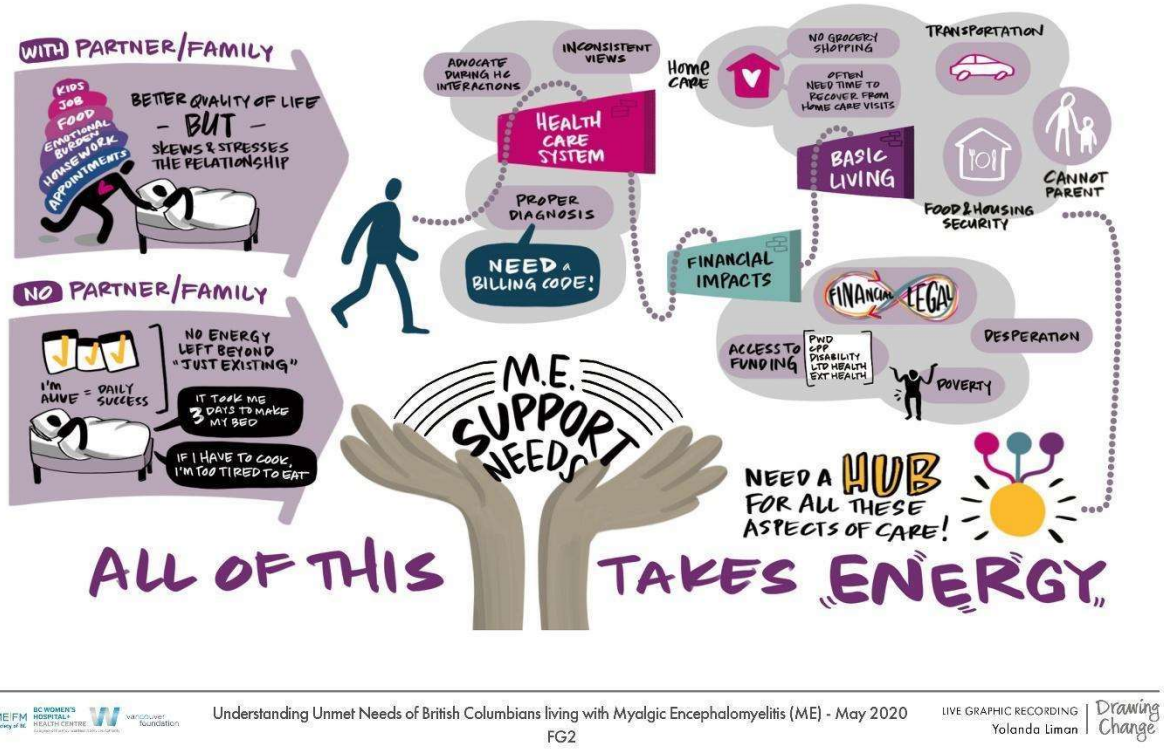
> *"All of my spare time is spent just in the dark basically, and alone."*

Loss of social connection was part of a larger loss of identity to ME patients. Not being able to work, parent, volunteer, pursue hobbies and continue with physical pursuits was expressed by many as a complete shift from their life prior to illness. With illness it is expected that some life adjustments occur, however, ME patients described a complete loss of life:

> *"… it's impacted my life in every aspect of it. From who I feel I should be, to my career, right down to my relationships with my friends and family and strangers. Yeah, I don't think there's one part of my life it hasn't touched or changed in some way and forced me to rethink or re-evaluate and I know that if I didn't have it I would be a very different person than the person I am."*
>
> *"I feel that I am no longer able to do the things that used to make me 'me'. And I feel a real loss of personhood because of that. I feel now it's really hard to distinguish what is the illness and what is me."*
>
> *"Kind of tortured by it actually because … at the same time I feel like it's changing my personality. There's still that core of me that expects me to be me every day. Or the same me that I used to be."*

The conversations about social isolation and loss of identity lead many patients to discuss emotional health support needs. Patients suggested having ME accessible support in place to help with emotional wellness and support connection. Some patients had positive experiences in connecting with other patients in online social media platforms to gain help with navigating the health systems or symptom management help, yet other patients disclosed that they didn't know anyone else with ME. Peer groups, which are "ME friendly" and "ME aware" were suggested as they could offer more empathy and understanding compared to generic mental health support groups. Additionally, patients proposed the value in having trained mental health professionals facilitate such groups but also have these groups modeled in such a way to support ME patients. Specific suggestions included: waiving appointment cancelation fees as they are often inevitable due to illness unpredictability; if in person, low light, rest breaks; telehealth to reduce travel; costs to practitioners are high and more ME patients are not working so limited funds or benefits; and that practitioners be trained to help with particulars of living with ME.

Support for ME and how to live with ME



"People have used the word resilient to describe me but I realize that is everyone with ME. That's our middle name, right?"

Patients described how inaccessible and scarce typical health-related navigation and health care system support was for them as ME patients as compared to other disease groups (e.g., cancer, MS). There did not appear to be a difference expressed by patients regarding the available support between those patients rurally located or urban. Left to navigate their own care independently, ME patients shared how they were left to search for information, to research symptoms and treatments, to bring information to their family doctors, to find other doctors, and to find other patients to learn from. Participants repeatedly noted that there was not a clear path of treatment and that treatment was associated with unclear expectations. This was a "hard road" for patients as self-navigation was physically and mentally demanding, which furthered their exhaustion and lowered their health.

> *"I know I would not be in a wheelchair if I had stopped pushing earlier, if I'd had an answer earlier. I think my life would be different. I think-- I don't think it would be easier by any means. It's still living with ME. But I think if the resources had been made available and if the understanding had been there, I-- yeah, I think you'd be talking to a different person, to be honest. I think I'd have more of a life than I do now. I don't know what it would look like. But I know it would-- I would definitely be doing more."*

The inconsistency of the health care system and the continual dismissal of the patient experience by clinicians left patients continuing to seek support elsewhere. ME patients described themselves as needing tenacity, resilience and perseverance on their individual

diagnosis path and symptom management efforts. But that tenacity came with a cost to their health:

> *"If my GP would have known more, I may not have pushed myself so much, because pushing myself made me worse."*

Patients described significant struggle and hardship at every turn. Diagnosis and medical system access, as above, is a significant challenge, as is day to day life. Support for ME patients was varied. One marked distinction of support was whether the patient lived alone or not. For those with a partner or family member, the patient was supported in their daily living - often solely by this individual, to include food shopping and preparation, yard and housework, and often financial support. Patients recognized the toll this took on their family member, and how it skewed their previous relationship and living arrangement. Regardless of living arrangements, it was consistently described that life with ME is *"day to day life"*.

In contrast, those patients living alone described incredible challenges to maintain safety and health in their living arrangement. Patients described some of the challenges of living alone with ME:

> *"Bed making may take three days, one day to strip the sheets, second day for laundry so sleep on a bare mattress and third day to put it back together."*
>
> *"If I have to cook my own food, I'm often too tired to eat."*
>
> *"I often go to bed hungry as I feel too unwell to leave bed for food in the kitchen."*

Those patients that had some type of live in support were seemingly more able to seek out resources compared to those living alone who noted they were "*just coping*" with activities of daily living.

Some patients living alone described attempts at having community-based support into their homes (e.g., homecare). However, the homecare services either were an ill-fit (e.g., not able to do some of the needed tasks due to out of scope):

> *"I don't have laundry and they [home support] weren't allowed to leave my premises to go to the launderette so I had to pay them out of my disability."*

Or that the lack of ME education and awareness by the hired individual rendered too much added sensory stimuli and the patient *"would have to rest for days after a scheduled appointment"*. These patients also described challenges in getting to medical appointments themselves.

Patients living alone described that there are "*just existing*". The activities of basic living were all encompassing for their energy levels. Most patients expressed financial hardship. Those living alone held particular concern with worry that without some support they would likely enter poverty. Those living with a partner or family member acknowledged that without them, their lives would be significantly impacted in the negative.

Neither group, patients with or without a partner had much comment to offer about a backup plan. There was no respite in place for the partners, no plan if the spouse was no longer in the home, and those living alone also didn't offer any known contingency plans. Interestingly, many patients listed legal support being a significant part of their support strategy. Many ME patients cited facing denied applications to provincial or federal

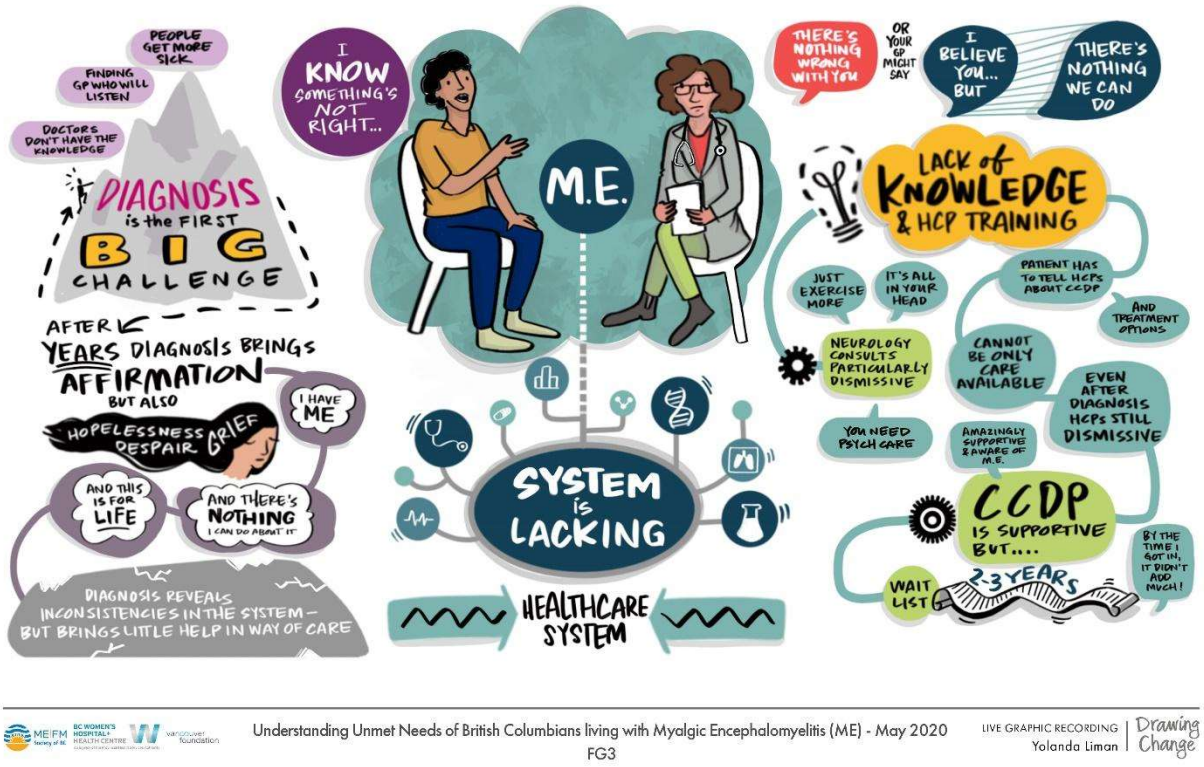
disability, and/or long-term disability insurance programs, which results in financial insecurity. Many ME patients indicated they could not afford to hire help, while others were not eligible for no-fee home support due to criteria limitations (e.g., could dress themselves). One patient described their constant struggle:

> *"We are fighting to be acknowledged, and fighting for coverage."*

Patients suggested a multi-focal hub for centralized care, inclusive of support for financial, insurance and legal support akin to other illnesses such as MS, diabetes, arthritis. Patients were aware that there wasn't a billing code for ME, and that this was indicative of a lack of support in the medical system for their illness.

Patients observed how the medical system has adapted for COVID-19. They commented that now with telehealth they have improved access to their family doctor. But they also noticed how fast public awareness and research funding has occurred for COVID-19, and billing codes. This is everything the ME community has been pleading for, for many years yet without response.

Challenges of diagnosis



The challenge to receive a correct diagnosis is an overarching theme to the patient experience. Most patients expressed that it had taken years for a diagnosis of ME. The path to an ME diagnosis was often lengthy and challenging as it was not straightforward from the health system with few practitioners knowledgeable or confident to diagnose. While patients get referred onward in multi directions, this effort negatively affects their health and they are often met with stigma and dismissal or exclusion from the health care system. Not one patient discussed an early and accurate ME diagnosis. Patients stated with grief that they were very aware that the ME diagnosis was without a cure. Patients described their lengthy investigative path using resources that were unnecessary:

"I spent probably three and a half, four years with her doing every kind of test you can imagine. I went to a neurologist. I went to a gynecologist. I went to another doctor, I don't remember the name of, that was specifically for hormones and stuff. I went to a respirologist. I've had MRI's. I've had CAT scans. I've had, like, they've done so much crazy workup and all of the stuff was coming back mostly inconclusive and 'you're fine, you're fine, you're fine'."

Some patients indicated that they had to bring information about the one provincial program designated to work with ME patients (CCDP) to the physician. It was patient-driven research (mostly, internet based) to find an option for patient support.

Obtaining an ME diagnosis, while validating, continued to be a rollercoaster as patients then discovered there is no treatment for ME. Patients described feelings of despair, frustration and grief knowing the current medical system could not support their health and care in that what was ultimately offered is self-directed and self-managed care. One patient described feeling quite angry about the diagnosis as it was then understood how little is available for ME, and what an "appalling" journey it was to get diagnosed.

"I felt relief when I was diagnosed because I finally had a name. My mind had gotten very dark because of the pain and sleeplessness was so challenging. I couldn't find what to put together myself of what was wrong. But as I learned what that was, there then was a letdown because there wasn't a cure. Disappointing is not the right word. I had lost so much life. It is sadness. "

As the only provincial referral centre for people living with ME, the CCDP was mentioned often by patients. Often their ME diagnosis came from the CCDP. The physician engagement at the CCDP offered validation and allowed for some connection and support from the interdisciplinary team. For some, attending the CCDP was positive and validating:

"The CCDP was the first experience where I was taken seriously and offered positive validation. I have been mistreated by so many doctors before that."

". . . it just became impossible to ignore it and I became more and more determined that I had to figure out what was happening. And so, I pushed and I pushed and I pushed. And after 26 months on the waiting list at the CCDP I was diagnosed."

Unfortunately, there is high demand of the program, resulting in lengthy wait times, which were articulated by several patients. Some patients reflected that the program had not always met expectations. This may indicate high expectations for a curative treatment, which is not yet available, and re-enforces the need for research into the treatment of ME/CFS.

"I was at the Complex Chronic Disease Program and I had thought when I went there that that was going to be the answer to my problems. But it wasn't."

"By the time I got a call off the waitlist, I was much too ill to make it there to attend."

Some patients reported that their family physician didn't support a ME diagnosis, still "unbelieving" that ME is real. Patients described negative physician responses, especially, but not exclusively in primary care:

"…a doctor that took over for her didn't believe me and wanted to do all the testing again. And I just was kind of like well, if you're going to make me go through all of that again, I might as well go find a doctor who does believe me and work with them. It took three years to even find someone who would take me `cause at that point I had a diagnosis."

"My G.P. is not onboard. It's like-- I don't know if he believes in this disease."

"Most of the time when you say you have ME or chronic fatigue to a doctor, they make a disparaging comment or they look at you blankly. Or they ask you kind of slightly confrontationally, well, what is that? What does that even mean? Or they call the neuro psych or the psychiatrist to come and give you an evaluation."

"He doesn't do that (care for ME patients) because he finds it very draining as an internal specialist to deal with an invisible disease."

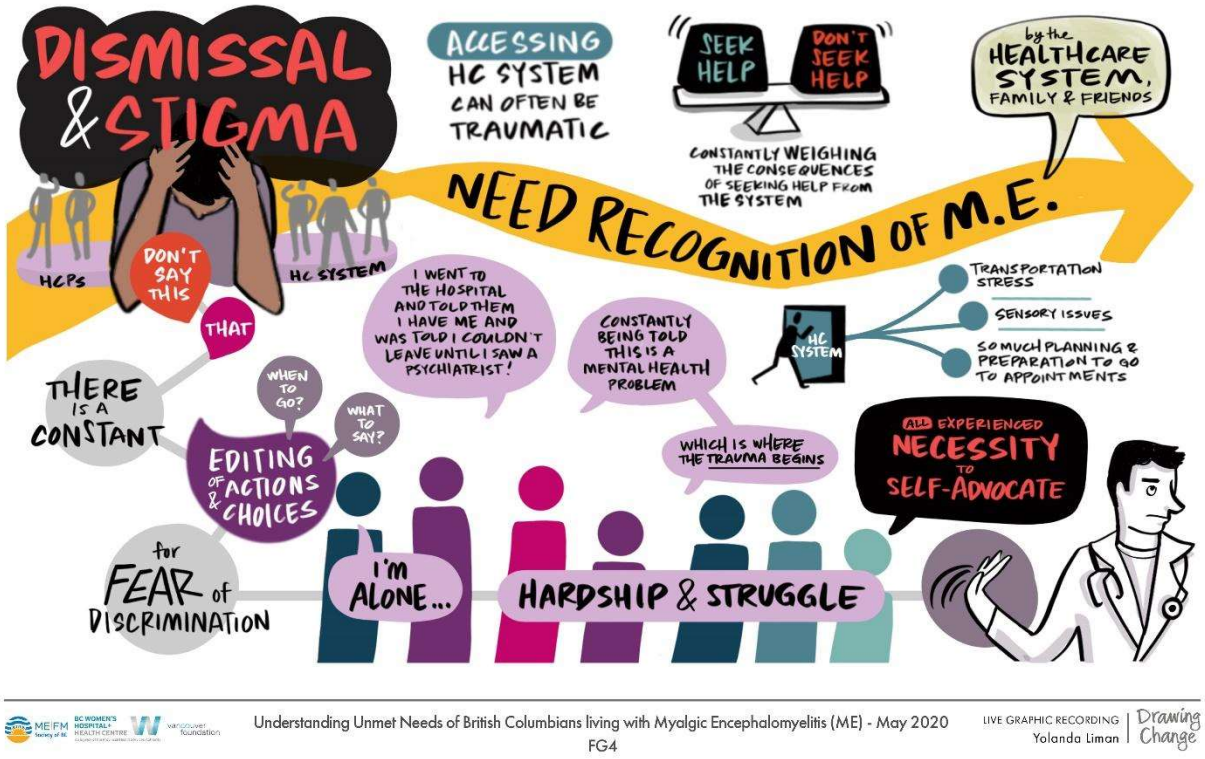
Patients voiced the need for an improved relationship with their family physician and looked to their physician to help navigate care. Some patients offered that the lack of specific knowledge about ME by many in the health care system could be addressed by increased knowledge and awareness of the disease. This is especially important to better legitimize ME in other aspects of the healthcare system (e.g., nurses, homecare, insurance). Patients are aware that there are no clinical resources for physicians. Some patients did describe the empathy and support found in their family practitioner, such as the practitioner became more open to reading materials presented by the patient, and to having helpful discussions on symptom support. Patients, who had physicians listen and believe their illness experience, felt supported:

"Because I have a doctor that listens and then he sent me to the POTS person and I was-- I do have POTS. So it's like every time I do that he listens more. He has more faith in what I'm saying, I guess."

"I need a doctor who believes in it. This is where the support starts"

"But it helped improve things with my family practitioner accepting she, like, most family practitioners had almost no knowledge of what ME was… she's subsequently been able to diagnose other people in the community with it in early stage illness or at least earlier stage illness. So that's been really significant."

Stigma in the healthcare system



Patients shared many stories when reflecting on their interface with the health care system. Feelings of dismissal by the health care system was consistent through patient stories. Patients shared how they make decisions on accessing care:

> *"I use my own term of PTDVS (Post traumatic doctor visit syndrome), because I have been so traumatized in doctor's offices that I arrive at a place where I wouldn't go unless it was absolutely necessary."*

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

Due to negative experiences with the health care system, patients detailed concerns, if not fear, to access the health care (for their ME or for other concerns). Patients shared examples of how they would not be disclosing their illness for fear of stigma, other patients described how they would restrain from accessing health care until it was utmost necessary. A surprising number of patients described how much and how often they avoided exposure to the health system. One patient described how saving extra medicine at home was their way of preparing for unexpected health events, explaining;

> *"I keep a big stash in the fridge. I keep expired meds and little bits of antibiotics that don't get used because if I can do it like that, I would rather do it like that than risk going to even my own family doctor and getting crappy care."*

Another patient described how any contact with the health care system could be potentially unhelpful:

"… when you do need help you know that you're going to wait until it gets really bad before you actually ask. You have to know that you're not going to be triggered. You have to expect to be. You have to anticipate that you're going to get a worsening of symptoms. That you're going to crash … if you have neurological symptoms, you're going to have an exacerbation of that. You're going to have severe post-exhaustion neurological episodes. You're going to have severe hyper stimulation and everything that goes with that. And it's almost counterintuitive."

Patients have to continually self-advocate to ensure their symptoms are taken seriously, that their access needs can be met (e.g., low light), even experienced patients expressed how disparaged or dismissed they were received.

"My GP said I was lazy and to go for a run, but I couldn't even do the stairs in my own home. I used to run every morning before work, and before I got ill. I am not lazy. I am ill."

Furthermore, the common diversion towards psychiatric care and the repeated notes of neurology consults being particularly dismissive was alarming.

"At a hospital visit, to get to the ER, when I told the admissions clerk I have ME she rolled her eyes at me. And then I waited hours. Once I was seen, I was told that I was making myself sick. It negated everything I was going through. They insisted that I had to see the psychiatrist before being discharged."

"I never discuss my emotional/mental health, I do that because of the game as HCPs have been trying to put my health on mental health. Which means pharmaceuticals. I self-edit that way to bring it back to ME, and not talk about my emotional health."

Patients are also looking to be taken seriously, and for ME to be routinely acknowledged by, responded and supported by the health care system. Patients want the disease they have to exist in the response of the health care system. One patient responded when prompted what is the ideal scenario when accessing care:

"When I enter any access point of the medical system I would like to be met with 'Oh, you have Myalgic Encephalomyelitis. That is a multi- system disease. That can be quite serious."

Patients communicated the necessity for clinicians within the health care system, to recognize the historical lack of belief in ME patients. They noted that prior lack of care and health care system failures may further inhibit patients' ease in entering into new clinical relationships. Patients feel hopeful for improved ME awareness and education in the health care system and, at the very least, they need renewed confidence that they will be listened to when accessing care. Patients also put forward the anticipation that as the health care system improves awareness, overall public awareness will follow

Clinician Survey Results

An electronic survey resulted in 173 responses from clinicians throughout all health regions in BC. Professional categories represented 53 (30.6%) physicians, 39 (22.5%) registered nurses, 26 medical specialists (15%), 26 allied health professionals (15%), 5 (2.9%) administrators, and 3 (1.7%) nurse practitioners. Responses from the five main survey questions provide a helpful

introductory examination at the level of knowledge, confidence and experience in treating ME patients in a clinical setting in BC.

Clinicians self-rated their knowledge of ME on a Likert scale of 1 (no information) to 5 (know very well). With the majority of respondents (139, 80.3%) indicating moderate to no knowledge of ME, 91 (52.0%) clinicians indicated they had interacted with a patient with ME in their practice and 33 (19.1%) clinicians were unsure if they had or not. Confidence in diagnosing and treating ME was low, with 76 (43.9%) clinicians indicating no confidence to diagnose and 52.6% of clinicians not confident to treat ME patients.

Two open ended questions were included in the clinician survey. The first question asked for opinions about how best to address the needs of ME patients and/or the health system. The second question remained open for respondents to share any further comments related to the practice/treatment of patients and/or ability to manage or care for a person living with ME. Approximately half of the survey respondents took the opportunity to provide comments.

Clinicians offered common recommendations for clinical care improvement for ME patients including: 1) improved practitioner education, 2) improved diagnostic and clinical guidelines and 3) increased access to referral resources (e.g., community care, allied health care). Examples of how clinicians view the current challenge of ME/CFS patient care:

> *"Would like to see guaranteed biomedical education about ME in the health professional education curricula, including physician, nursing, pharmacy, PT, OT, as well as regular education supported by the registered colleges for the professions and specialties. There remains a strong psychological bias, especially from neurologists, and clinicians don't know how to diagnose or treat patients with ME/CFS"*

> *"Practice guidelines as there is no standardized approach for treatment options and no real guidance of what to offer patients or their families."*

Some opposing views of central vs decentralized care were present in the comments. However, many respondents stated the current provincial referral option (i.e., CCDP) has too long of a waitlist and the lack of alternative care options is problematic:

> *"There needs to be education and resources available. The chronic complex diseases clinic at Women's has a 2-year waitlist, and there really is no alternative. The condition is stigmatizing and I have encountered quite a few physicians who do not believe in the diagnosis and therefore their patients are left underdiagnosed.*

> *"Really feel these people slip through the cracks especially in a setting outside of the major centre. It was suggested my patient go to the clinic at Women's in Vancouver, but she really finds it hard to travel. I am trying to find local resources but don't know what this would be outside of limited home care support."*

Somewhat common was the concern with this population is that there is not a specialist "home" for these patients and that this contributes to the stigmatization of these patients:

> *"CFS / ME does not have a home in the medical hierarchy. It probably should be under internal medicine, but since most internists probably*

consider it to be a somatization disorder it gets marginalized. Without a home in the hierarchy, patients will continue to be stigmatized and necessary research will never get adequate funding.

"Need physicians specialized in the area. Many physicians still don't think it is real- when it is. These patients need to be supported by physicians who understand and care. Not punted around."

Other suggestions include very specific ways to support patients such as wanting more patient self-management tools, validating patients, increased support for disability/insurance paperwork, provision of support groups for patients and other practical support options.

"It has been frustrating trying to manage these patients because of lack of community support services they can access."

"I think we need to be more willing to meet our patients halfway and recognize their suffering and our own limitations."

Process Outcomes

COVID-19 impact

The unforeseen public health emergency of COVID-19 began within the timeline of this project and required any in-person project activities to be adjusted. Originally, in-person interviews were planned, as was a full day World Café event that was aimed to bring together both patients and clinicians. The project had anticipated offering attendance support (such as honorariums, travel stipends) and planned for patient respite accommodations (such as quiet rest rooms with cots). However, with consultation among the Project Team, the project moved forward to all online/virtual community engagement. Thus, it is unknown how a World Café format would work for ME patient and clinician stakeholder groups together.

Mindful that a global pandemic could hold impact on an already vulnerable population such as ME patients, the Project Team reviewed and prepared with as much sensitivity as possible. The COVID-19 pandemic, and its restrictions, did not seem to encumber patient participation in our project (April and May 2020), and the healthcare practitioner survey participation was stronger than anticipated.

Methodological learning

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. Patients expressed gratefulness to participate overall, and also from their own homes. Email communication to confirm participation, gain consent and introduce online technology was successful. Providing technology support in advance (such as having a 5-10 minute pre-focus group connection time), with ease of time pressures, supported patients with attending online. All patients were able to connect as instructed. Smaller focus groups were anticipated to be generally easier on patients. Five focus group participants for 60min sessions was an appropriate structure to consider in future. Severe patients were able to participate in a reclined position (bed or couch), and other participants to move within their home to alternate sitting arrangements with ease. This was seen as allowing the data collection process to be very patient-centered and supportive.

Clinician recruitment occurred through electronic communication. The project staff located within the CCDP/WHRI developed an announcement to be placed within existing site-based communication (e.g., E-blast). This internal promotion to a broad range of hospital staff was successful and began generating responses. More "cold contact" of other provincial clinician agencies/organizations was also done by the Research Coordinator. Mixed results in responses of the request to share the announcement were received. Some outreach resulted in no response, some with an explanation that it is outside of the individual agency's mandate to advertise external projects, and some were very willing. The survey was supported by both the Division of Family Practice and Doctors of BC and promoted via multiple electronic communication mechanisms (e.g., Twitter, blog post, and email). This also generated survey engagement. Considering the known challenge to engage clinicians in surveys, and with added concern of the summer timing and during a pandemic, it was unknown what attention the survey would receive. However, obtaining 173 responses with distribution by geographic areas and by clinician type, the survey recruitment and online methodology was deemed successful and satisfactory.

Project Limitations

This project invited only patients with an ME diagnosis, yet it is known many patients struggle to obtain an official diagnosis from a physician. Therefore, the patient experiences of those with ME in the community but still without a diagnosis are not represented. Also, patients who are able to receive and read emails, be alert to websites for announcement of the project and those able to participate in a one-hour phone call are not necessarily representative of all ME patients in the province. For example, these views presented would may under-represent patients who are too ill to participate for an hour long session, and others who may not be connected to the ME/FM Society of BC social media and email. Patients pending a diagnosis, or mild in disease severity may not be connected to the community through the ME/FM Society and therefore would not be recruited to this project. Additionally, those individuals responding to participation requests are potentially in support of advocacy for ME patients, thus the population not attuned to ME advocacy may not be represented.

This project only engaged with 25 patients, yet the Canadian Health Survey indicates there could be an estimated 77,000 individuals with ME in British Columbia)[2]. Recruitment was conducted through the ME/FM Society and therefore not random. Recruited individuals from the Society may be more likely to engage in advocacy, and may have a higher capacity for information finding, than the general ME population. They are also able to read and respond to electronic communication, and participate in hour long conversations; this is not true of all ME patients, particularly the very severe. However, most participating patients in this project self-reported their disease severity as more moderate towards severe disease impacts (many homebound or mostly bedbound) and thus, those patients on the mild spectrum of ME patients were not represented. Further, the clinician survey represented 173 professionals: 79 doctors (family physicians/specialists) and 42 nurses (RNs/NPs) as the majority of respondents. This is a fraction of the province wide professional population. Additionally, it is unclear if the survey participant demographic were those professionals already involved with ME patients, caring for ME patients or those who have some interest in ME. This project is a small representation of each demographic and as such findings are limited to this group and cannot be extrapolated across all patients and health

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professionals in the province of BC. A larger, more expansive project would allow for greater depth of inquiry, broader participation and clarity of conclusions.

Key Findings

Patients' experiences of living with ME is dire alarming, and urgent. ME patients in the sample have gained strong self-advocacy skills and personal resilience to seek understanding of their health. Despite their tenacity, an ME diagnosis can be an isolating experience with a dire outlook. The lack of medical and public awareness for ME may contribute to the limited support to patients in their illnesses. ME patients have limited energy and their illness further declines with exertion, yet these patients are repeatedly left to self-navigate, self-advocate and self-manage their own care.

Patients feel they receive limited help from the health care system's poor awareness of ME. ME patients are often very ill and poorly served by the health care system. Experiences of disbelief and further deterioration of health is occurring from delays in disease recognition in primary care and inconsistent use of diagnosis pathways. This will continue as long as there is a lack of awareness and subsequent recognition of ME across the healthcare system.

Both patients and clinicians acknowledge an unacceptable lack of available clinical care options. From their different perspectives, both patients and clinicians shared the same need for improved clinical support. Patients need to be better cared for and clinicians want to provide informed care.

Clinicians expressed a desire for improved education for ME care. Clinicians expressed a need and interest to be better supported in providing clinical care to ME patients. A willingness for education pre- and post-licensure was expressed.

Conclusions

This preliminary project began to explore the experience of ME patients and clinicians relating to ME care in BC. The sample of patients and clinicians engaged in this topic highlight the need for further expanded research and exploration of barriers and facilitators in ME care delivery in BC. The CCDP and some individual community physicians are working to support ME patients, yet many patients included in this project, despite their own tenacity and resourcefulness, described not feeling adequately supported. The limited care – compounded by insufficient clinical knowledge or system gaps – results in a system that does not seem to fully meet the needs of ME patients. Patients in this project expressed experiencing a high level of stigma and/or dismissal at many interfaces within the healthcare system. Clinicians engaged during the course of this project expressed a strong interest in improving clinical education, referral resources and broader support for patients with ME in BC.

The secondary aim of this project was to test the feasibility of mechanics and engagement with this particular patient and stakeholder population. The Project Team was successful in using social media to recruit patients (for interviews) and clinicians (for survey). The willingness of both patients and clinicians to participate in this project cannot be overstated. This project experienced successful adaptation of virtual research methods (e.g., online interviews, focus groups, electronic survey distribution) which could be reproduced in a larger, future project. There were unanticipated levels of engagement in both the patient invitation and the practitioner survey. The success of this project's

engagement with key stakeholders serves as a strong indicator that the needs of ME patients and care in BC is important, relevant and deserving of future attention.

Next Steps

"I'm not giving in to this. It's not taking every single thing away from me. It's taken so much, but it's not taking everything." – Patient

As a Project Team, the next steps for this work is three-fold. First, this project has served as a seed for more comprehensive work. The results have indicated the importance in moving forward to a larger, more robust provincial needs assessment. Second, it is imperative that we seek funding for future research, which we will do through requests to, the BC Women's Health Foundation and the Vancouver Foundation. Further funding sources will also be explored. Third, it is essential to discuss a plan for disseminating these results to various stakeholder audiences. This is critical in order to mobilize ME stakeholders (patients, providers, health care decision makers, and health research funders), across BC.

Strategically, this project has produced social media "friendly" infographics that summarize our results for distribution on various channels. Also, targeted summaries could be developed to help further share this data collection. We have piloted methods for this project, which have deemed feasible and can be repeated in a larger, province wide project and elsewhere (e.g.., in other provinces). We have received interest in sharing these methods/tools. The Project Team will discuss feasibility, intentions and timeliness to pursue future funding opportunities and directions.

This project identifies multiple directions of inquiry that are relevant and necessary in improving ME awareness and clinical care for patients in BC and beyond. A preliminary roadmap for a health needs assessment for ME/CFS in British Columbia has been developed (below). This roadmap will serve as a discussion framework for the future application effort of the Vancouver Foundation's Investigative Grant.

A Roadmap for a Health Needs Assessment for ME/CFS in British Columbia

A large scale, provincial health needs assessment (HNA) for ME/CFS in British Columbia is planned, subject to funding. This will aim to be a systematic, rigorous approach to identify the unmet health and health care needs for the ME/CFS population. The ME/CFS HNA will also aim to identify opportunities of improvement and change at the patient, provider and system levels. Patient partnership was a core principal and was evidenced in every aspect of this Convene project, and remains a fundamental relationship looking forward to a full ME/CFS HNA. Below we outline seven areas that will need to be addressed in the full needs assessment.

1. Demographic and health data on the target health region:

Currently, all prevalence, mortality and morbidity estimates related to ME patients in BC are based on national estimates and/or other international estimates. Further, there are issues identifying ME patients in provincial administrative data, such as no billing codes and problems achieving correct diagnosis. It is important to explore the problematic context of this factor in a larger context.

Generate prevalence estimates of Myalgic Encephalomyelitis in British Columbia, then stratify by geographic region (e.g. provincial health authority):

a) Estimate the key epidemiological indicators for the burden of disease for ME, and the potential effects and cost-effectiveness of specific interventions.
b) Then produce an overall model of epidemiological outcomes based on disease prevalence. Model should reflect both detections and non-detections of ME in the current health system landscape.
c) Estimate mortality and morbidity, including disease duration and severity and estimate economic impact for individuals and society. Loss of productivity due to mortality and morbidity of disease can be calculated using standard formula to estimate the economic impact to individuals and society.

2. A targeted assessment

The pilot project suggested that while there are some successes in the healthcare system related to individual ME patients, there are also deficiencies or barriers to care. Responses in all participant groups (patient and clinicians) suggested an eagerness and willingness to support further exploration. The team identified the need to consider health service delivery in the following areas:

a) Policies
b) Programmes
c) Services and interventions in terms of their availability
d) Quality
e) Coverage
f) Effectiveness and cost-effectiveness of interventions

3. Describe the current state of health system access and support:

The pilot project suggested there is a lack of concrete data related to efficacy of care in health service delivery to the ME population throughout BC. The pilot project explored qualitative data from both patient and health care stakeholder/clinician populations and concluded the importance of the describing the following:

a) A comparison of the current situation ("where are we now?") with the desired situation ("where do we want to be?").
    - Summarize Step 2a to describe current state of health system
b) Then list potential actions to address identified gaps and unmet needs for the ME patient population and stakeholders.

4. Qualitative assessments of the effectiveness of current interventions:

The pilot project suggested that engaging stakeholders through electronic means, such as email/social media recruitment, online survey completion, and virtual interviews/focus groups was successful and fitting to these groups. In particular, remote accessing this patient population encouraged and facilitated participation:

a) Engage with patient partners and health system stakeholders to assess and complement and interpret information provided above. The goal is to provide a qualitative view of the gaps in needs and in the operation of health services, including the effectiveness of current health care resources available to the patient population and stakeholders.

5. Moving to prioritization and action:

The HNA project timelines are expected to be phased within a 3 year period. In the third year of the project it would be important to identify and target problem areas and

interventions by working to resolve service gaps. They should be relevant and appropriate to the economic and geographic factors in the health region. These interventions should be sensitive to societal values, culture, and local legislation. Discussions and decisions regarding prioritizations will include: Setting ground rules for discussions, involving a diversity of stakeholders, define the criteria for priority setting, and setting aims and objectives for prioritization, and formulating an implementation plan:

a) Moving to action: First specify the action, then expected results from this action, and finally define milestones to track how this action can be assessed in the future.
b) Evaluate impact on action taken, based on pre-determined outcomes.
c) (items c and d go beyond the initial health needs assessment exercise)

6. Overall Project Planning:

Finally, as a framing for the expanded stakeholder / project team the determination of the following are required:

a) Determine the aim and scope of various steps of the HNA, from selection of stakeholders, data collection, up to the priority setting exercise and decision on priority action
b) Compile a project budget, seek advisors for budget planning
c) Determine locally (e.g., notable geographic differences) relevant decision making criteria
d) Create an overall Project Advisory Team to identify options in terms of:
    - Areas for service growth
    - Areas for resource release through producing same level of output but with less resources
    - Areas for resource release through scaling back or stopping some services
e) Enlist Project Advisory panel to make recommendations in terms of:
    - Funding growth areas with new resources
    - Decisions to move resources from funded resources to new areas of service growth.
    - Trade-off decisions to move resources via stoppage/scale back of services to new areas of service growth.
f) Validity checks with additional stakeholders and final decisions to inform budget planning services.
g) Determine the project conclusion dissemination strategy.

7. Produce a Health Needs Assessment stratified by geographic region that summarizes previously identified areas in the prioritization and action section.