



Association pour la santé environnementale du Québec
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Lived Experiences of Multiple Chemical Sensitivity: Summaries from Focus Groups

In the realm of health conditions, few are as misunderstood and misrepresented as Multiple Chemical Sensitivity (MCS), a chronic condition characterized by heightened sensitivity to various environmental triggers, such as chemicals and fragrances. The misconceptions surrounding MCS not only contribute to stigma but also pose significant challenges for individuals living with this condition.

Recognizing the pressing need to address these misconceptions head-on, we facilitated a series of focus group discussions, providing a platform for individuals affected by MCS to share their experiences firsthand. Our participants bravely shared their stories, shedding light on the daily realities of living with MCS.

As we listened to their stories, it became abundantly clear that the pervasive misconceptions surrounding MCS are not just damaging—they're debilitating. From facing judgment and skepticism to encountering barriers in accessing essential services, individuals with MCS endure a myriad of challenges due to the lack of awareness within society.

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In compiling this summary, our goal is twofold: to amplify the voices of those affected by MCS and to challenge the misconceptions that continue to perpetuate stigma and discrimination. We hope that by sharing these firsthand accounts, we can encourage greater awareness, understanding, and empathy for individuals living with MCS.

We invite you to explore the insights shared in this summary and to join us in our mission to combat misconceptions, break down barriers, and create a more inclusive and supportive society for individuals with MCS.

The focus group sessions were conducted in small groups over Zoom, to ensure inclusivity and accessibility for all participants. In total, 30 participants took part in these sessions. Demographically, the average age of participants across all sessions was approximately 60 years old, with ages ranging from 40 to 80 years old. The sessions provided a platform for individuals primarily from Ontario, Quebec, and British Columbia to share their lived experiences and perspectives on various topics related to MCS. This geographical representation ensured an understanding of the challenges faced by individuals with MCS across different provinces.

The focus group discussions were organized around three main topics, each conducted at different time points:

1. **November 2022:** The focus was on exploring the experiences and needs of individuals living with MCS.
2. **January 2023:** The discussions centered around accommodation measures and strategies to support individuals with MCS in their daily lives.
3. **January 2024:** The focus was on prevention strategies aimed at minimizing exposure to triggers and improving overall quality of life.

Throughout our focus group discussions, several key themes emerged, reflecting the shared experiences and challenges encountered by participants.

1. Environmental Triggers

Environmental triggers, such as scents and chemicals, present a major challenge for individuals living with MCS. These triggers, ranging from fragrances to cleaning products and laundry detergents, surround us everywhere and affect every facet of daily life. This makes them virtually impossible to avoid and profoundly impacts the ability of people with MCS to engage in routine activities and access essential services. It's a constant battle to avoid these triggers, but they're everywhere – in homes, public spaces, even outdoors. Participants shared their struggles navigating public spaces like grocery stores or pharmacies. The overpowering scents and cleaning chemicals often make these environments unbearable. Additionally, the risk of



chemical contamination of food items further compounds these challenges, as staff or other customers may touch food items after exposure to chemicals. Once contaminated, these items can no longer be consumed and must be thrown away. Even simple activities, such as going for a walk or meeting friends, can become overwhelming and disabling due to the presence of triggers introduced in the environment, such as perfumes from laundry products emanating from dryer vents, which perfume the outdoor air in the neighborhood. This makes even enjoying any activity outdoors on a patio, or gardening, impossible. Participants vividly described the overwhelming impact of these triggers, and the far-reaching consequences of MCS on their lives.

“And each time I'm exposed to something like this, it makes me even more sensitive. So it's like packing the bricks on my back like every single time it gets harder and harder to even go out there.” - Focus Group Participant, November 2023

“I know that I'm gonna have to come home and air my clothes out for the next maybe week, because it's the fragrances have stuck to my clothing. And you know, I have to shower as soon as I get in the door. Otherwise, I'm going to be you know, have a serious migraine, and trouble breathing for the rest of the night.” - Focus Group Participant, November 2023

2. Effects on Physical Health

In our discussions, participants shared stories of the profound physical suffering they endure on a daily basis. These symptoms, which vary widely among individuals, are debilitating and significantly disrupt their ability to lead a normal life. When encountering triggers, they reported experiencing effects that could last for days. These symptoms ranged from anaphylactic shocks and unconsciousness to cognitive impairment, with additional reported symptoms including nausea, heart palpitations, vomiting, and heightened sensitivity to various stimuli. The range of symptoms reported by participants affected multiple bodily systems, including respiratory, gastrointestinal, skin irritation, and cognitive functioning. Some described severe and long-lasting pain, muscle spasms, and chronic co-occurring conditions such as asthma, which further compounded their health challenges. Moreover, participants frequently highlighted the profound impact of MCS on their overall well-being, citing extreme fatigue, unrestful sleep, sinus irritation, and fluctuations in blood pressure as common struggles.

“There's been a couple of times that I've almost called an ambulance, and I get confusion and just irritability and headaches. I get these migraines now. The doctor thinks this whole eye situation are these migraines that I've never experienced before. I had regular migraines from food, but this is a different kind of migraine, which kind of makes you very disoriented, but it's a horrible situation.” - Focus Group Participant, January 2024



One of my worst symptoms is pain. I have full body pain everywhere, every inch of my body, 24 hours a day, because I never get a reprieve. It's all kinds of pain, like joint pain, nerve pain, muscle pain, muscle tightness. The worst is probably, I call nerve pain. It's a burning sensation throughout my whole body. It's almost like a brain freeze or a toothache. Everywhere on my whole body, 24 hours a day. I can't even believe I've lived through this for 30 years. The pain is so - I would call it ungodly" - Focus Group Participant, January 2024

"It feels like someone slammed me up against the wall, or I've been run over by a truck, or everything is just in agonizing pain and be like that for days. I can have an asthma attack. I can have tremors when I'm going through a reaction, all kinds of different things." - Focus Group Participant, January 2024

"They often ask what it's like, it's a headache that comes on, lung problems, eye problems, it burns. Yeah, the minute I get home, I have to wash up." Focus Group Participant, November 2023

3. Attitudinal Barriers

Individuals with MCS face relentless attitudinal barriers, stigma and discrimination stemming from widespread ignorance and lack of awareness. These barriers impose a heavy toll, requiring individuals to continuously advocate for themselves. Many describe this task as exhausting and frustrating, as they routinely encounter negative perceptions, confrontations, and even accusations of harassment. One of the most damaging misconceptions about MCS, unfortunately widespread, is its attribution to psychological causes. This misconception not only generates discrimination but also results in distressing experiences. Their struggles are dismissed and invalidated, leaving them without the support they desperately need. Another prevalent misconception equates MCS solely with sensitivity to odors, whereas in reality, it is triggered by exposure to chemicals, including those present in scents. For instance, some may believe they adhere to a scent-free policy, unaware that certain products labeled as fragrance-free contain chemical masking agents, thus perpetuating stigmatization and misunderstanding. The consensus among participants in our discussions was clear: a robust education campaign is needed to dispel misconceptions, educate the public and policymakers, and promote a deeper understanding of MCS from both medical and societal perspectives.

"You've tried to take, you know, my human rights on an individual basis, one at a time, but it's it's exhausting, period, but especially for people who are already ill. And I find when you try to do that you encounter barrier after barrier systems that are in place to help you oftentimes end up letting you down." - Focus Group Participant, November 2022



"I actively advocate this every chance I get. And so I'm constantly being accused of harassment and everything. So it's, it's really hard to deal with." Focus Group Participant, November 2023

4. Lack of Healthcare Support

In healthcare settings, the lack of understanding about MCS is particularly damaging. It's unanimously recognized as one of the most pressing challenges, as many healthcare professionals remain unaware of MCS or fail to recognize it as a legitimate medical condition. There's a concerning lack of knowledge among healthcare professionals regarding MCS. Countless individuals with MCS struggle to find doctors who understand their condition. This struggle often leads to delays in diagnosis, difficulties accessing appropriate treatments, and consequently worsening health conditions. This knowledge gap stems from MCS not being included in medical school curriculum, resulting in a lack of training among physicians. This leads many individuals to avoid seeking essential medical care, as doctor's visits can often make their condition worse. Factors such as the presence of chemicals and fragrances in waiting rooms and treatment areas, and those used by medical personnel, coupled with negative interactions with doctors who dismiss their concerns as mental health issues, were highlighted as particularly distressing experiences. The burden of constantly advocating for their health needs and facing resistance from doctors can be incredibly stressful, with some choosing to forego medical care completely.

"So we're always defending ourselves, taking responsibility for our own health, and that's not easy for everyone. I have women who have completely given up. Now they're at home, they're letting themselves die and they've decided not to go for treatment." - Focus Group Participant, November 2023

5. Education and Employment

For many individuals with MCS, maintaining employment or pursuing education is a significant challenge, due to triggers such as chemicals, including those contained in scents, which are barriers to accessibility in the built environment. The economic consequences are substantial, with individuals experiencing job losses and decreased productivity resulting from exposure to fragrances and chemicals in the workplace, forcing many into poverty. While doctors play a crucial role in advocating for accommodations, such support is unfortunately rare to find. Doctors frequently refuse to provide necessary accommodations, hindering their ability to succeed in educational or workplace settings. Even in cases where workplace policies do exist, such as scent-free policies, they are often not enforced, leaving individuals with MCS frustrated by the lack of support. Consequently, many feel compelled to resign or opt for early retirement.



“My employer wanted me to wear a gas mask, and thought that that was a great alternative for me to continue teaching.” Focus Group Participant, November 2022

6. Housing Challenges

Securing appropriate housing is another monumental challenge for many individuals with MCS. Economic constraints resulting from employment difficulties often compel them to reside in unhealthy living conditions. Moreover, the presence of mold and exposure to scented products from neighbors, such as laundry fumes, cleaning agents, pesticides, and outdoor pollutants like barbecue smoke or wood burning, further limits their housing choices. Unfortunately, requests for accommodations often result in abuse, harassment, and discrimination, and in some cases intentional exposure to chemical products. This discrimination may come from landlords, neighbors, or even local authorities. Participants in our discussions highlighted struggles with local bylaws emphasizing the lack of recourse in addressing issues that directly impact living environments. Some individuals with MCS face the dire reality of homelessness, resorting to living in challenging conditions such as cars during the winter months to avoid harmful chemical exposure. One particularly distressing story was shared about a woman who opted for medically assisted death due to the lack of safe housing. Unfortunately, this heartbreaking case is not isolated, illustrating the profound consequences of governmental neglect and the urgent need for systemic intervention.

“There was a woman who struggled with MCS in Niagara Falls, a couple of cities away from me, for two years for doctors fought for her. And then she wound up using medically assisted death. And I think that that's deplorable, because she clearly didn't want to die because they were fighting just to get her safe housing. And that makes me sick. Like, why isn't the government doing anything about that” - Focus Group Participant, November 2022

“I feel like the entire world has become completely inaccessible. I'm fighting my former landlord on both the human rights and they sprayed stuff in the hallway that was intentional. They used Pine Sol, the building was moldy. I am fighting that battle. I don't have this energy. But this is what I'm doing.” - Focus Group Participant, November 2022

“I'm trying to find a place to stay for the winter, trying to figure out where to camp and stuff. I'm not in the safest housing myself, but it's probably better than trying to take a chance on something else, and finding myself in a worse situation. So I just sort of stay where I am.” - Focus Group Participant, November 2022



7. Social Isolation

In our focus groups, avoidance came up as the primary strategy used for prevention. However, this strategy comes at a cost. As a result, social isolation stands out as a predominant and deeply impactful challenge. Participants frequently express feelings of loneliness, isolation, and a profound sense of disconnection from their surroundings. The necessity to constantly evade triggering environments and social interactions becomes a defining aspect of their lives—a coping mechanism essential for survival. The detrimental effects of isolation are vividly portrayed, with many participants sharing stories of living in utter seclusion, emphasizing the toll this takes on mental and physical well-being. This constant need for vigilance restricts their ability to engage in their community or pursue hobbies, essentially depriving them of any meaningful activities. Despite these challenges, many choose to endure their symptoms to maintain relationships, creating an ongoing internal conflict. Adding to the burden of isolation are feelings of misunderstandings or stigma from others. Some participants expressed that their family members might attribute MCS to mental health concerns or dismiss their symptoms altogether, leading to a sense of disconnect or even invalidation of their experiences. This can create challenges within families, further exacerbating the isolation experienced by those managing MCS.

“Avoidance is what saves me from having a chemical exposure, which means instant and severe symptoms and feeling ill from that exposure for different lengths of time. Avoidance allows me to be well for a while until the next exposure shows up, often unexpectedly, and having no control over it. Avoidance also means avoiding people and places. It means having to give up my job and activities I used to enjoy, like going to movies, visiting family and social events.” - Focus Group Participant, January 2024

“Well, I'd go so far as to say almost total social isolation. In my case, it's even family members who don't cooperate. It's been so many years, human contact, at some point, just a hug from your sister or your son or a friend who comes for a walk, it would do so much good. You can't get close to people. No leisure activities. No cultural outings. We're restricted to home and TV. I mean, at some point, TV and radio don't feed your soul, you know.” - Focus Group Participant, November 2023 (French)

“As someone who lives alone, the impact is that I have no human contact. It becomes extremely, extremely, extremely difficult on a mental, psychological level. The impact is immense.” - Focus Group Participant, November 2023



8. Financial Burden

For people with MCS, the pursuit of a healthier and trigger-free environment that is essential for managing their condition requires significant financial investment. Many are already living in poverty due to difficulties maintaining employment, compounding the struggles they face. They bear the added financial burden of managing their condition alone, without adequate support. Individuals with MCS often face significant financial challenges in their quest for a healthier, trigger-free environment essential for managing their condition. Many are already living in poverty due to employment difficulties, compounding their overall struggles. Moreover, they often bear this burden alone, lacking the necessary support networks. Managing MCS and minimizing environmental triggers entail numerous additional costs. Enhanced building standards may be necessary to establish safe and supportive living spaces, free from harmful chemicals and irritants. Furthermore, the installation of specialized air and water filters becomes essential to eliminate potential allergens and pollutants. This also involves purchasing organic products or switching to least-toxic alternatives for household items like cleaning and personal care products. Many individuals with MCS also require specialized charcoal masks to filter volatile organic compounds (VOCs), as well as supplements and alternative therapies such as naturopathic treatments. Unlike conventional medical interventions, these expenses are not covered by health insurance, leaving individuals to bear the financial burden themselves, further straining their already limited financial resources.

“I’m literally going crazy. I don’t have enough to qualify for EI. If I get sick benefits and disability, it’s only \$800 a month. I can’t work more than \$6,400 a year. My rent is 1450 -I don’t like - Do you want me to just apply to die? Would that be a convenience for you that I end my life? I don’t understand.” - Focus Group Participant, November 2022

9. Impact on Mental Health

What resounded loud and clear is a message of struggle, exhaustion, frustration, and loneliness. Living with MCS exacts a profound toll on mental health. The perpetual stress of managing a chronic condition, coupled with the threat of unpredictable exposures, burdens individuals heavily. Social isolation exacerbates these challenges, leading to feelings of depression, intense loneliness, and a sense of abandonment. Financial strain resulting from poverty or inadequate housing conditions adds yet another layer of stress. The lack of support and understanding from various sectors of society deepens the isolation felt by individuals with MCS. This lack of support manifests in various ways, including dismissive attitudes within social circles, skepticism, bias, and stigma from healthcare professionals, as well as pervasive societal misconceptions about the condition. The exhaustive task of self-advocacy, where individuals must repeatedly assert the validity of their experiences and needs, often meets resistance and even hostility. This ongoing battle for recognition and accommodation creates a significant toll



on their mental well-being. Participants frequently vocalize feelings of fatigue and emotional turmoil, often acknowledging the suppression of their anger due to sheer exhaustion. These firsthand experiences underscore the pressing need for greater support and understanding for those managing MCS.