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Mental Illness and Structural Stigma in Canadian Health-Care Settings

Results of a Focus Group Study

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Contents

Section 1. What We Did

This report has been prepared as part of a larger structural stigma project undertaken by the Mental Health Commission of Canada (MHCC) to better understand how health-care structures create and maintain stigma toward persons living with mental health problems and illnesses and/or with lived and living experience of substance use. In this report, structural stigma refers to the accumulated activities of social structures and organizations that deliberately or inadvertently create and maintain social inequalities for people with lived experience.

The health-care system has been consistently identified as a contributor to mental health- and substance use-related structural stigma, as is manifest in

- insufficient funding for mental health services and research
- fragmentation and underservice
- use (some would say overuse) of coercive care
- health-care providers' poor knowledge of mental illnesses and possibilities for recovery
- diagnostic overshadowing where physical needs aren't adequately addressed.

Structural stigma in the health-care system contributes to poor quality of care and to disability and premature death.[1] However, its pervasiveness in Canada is difficult to understand without there being any coordinated attempts to document its scope and magnitude. Studies have examined how the Canadian news media negatively portrays people with lived experience. But no systematic efforts to learn how structural stigma plays out in the health-care system (and other sectors) have been undertaken. To begin addressing this knowledge gap, this study explored the personal experience of structural stigma by the people who are most affected. Its objectives were to

- gain a better understanding of the potential role of organizational practices in creating and maintaining structural stigma
- identify constructs that could inform the development of a generic framework to depict the nature of structural stigma
- inform the development of an audit tool that could be used to assess and monitor the occurrence of structural stigma.

The findings from this study will expand our understanding of the ways health-care organizations (and those working in them) may inadvertently stigmatize persons with lived experience. Given the existing gaps in our knowledge, this information will be useful to governments and health-system decision makers as they move to create non-stigmatizing health-care environments of the highest quality. In addition, information from this study will help developers create a conceptual framework of structural stigma in these settings, as well as an audit tool that can identify and monitor structural stigma in an effort to ameliorate it.

Our approach to data collection and analysis

Qualitative data were collected through three focus group sessions. MHCC staff members recruited participants from MHCC and partner advisory groups. Each session included five to 10 participants and lasted about 90 minutes. Relevant participants were selected for two meetings in Ottawa, piggybacking on other MHCC consultation activities. In terms of numbers over the three sessions held, five individuals participated in the first (two via conference call), 10 in the second (face to face), and five in the third (via conference call), for a total of 20.

Focus group participants represented a broad cross-section of people in Canada who had encountered structural stigma due to their lived and living experience of mental health problems and illness and/or substance use. They included youths, Indigenous peoples, mental health advocates, clinical care workers, and peer support workers. Many individuals occupied several roles. For example, some were also family members of persons with lived experience, including children who had died by suicide or overdose. Individual experiences spanned a range of inpatient, community, and advocacy settings in both mental health and substance use fields.

An external firm specializing in transcription was commissioned to capture the verbatim focus group conversations. The resulting transcripts formed the basis of the qualitative analysis. Data collection procedures received ethics clearance from the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Textual data were "open coded" using specialized qualitative software to identify discrete constructs reflected by words or phrases. These constructs were then synthesized and organized into broader themes.[2] The verbatim extracts included in the final report are anonymous and exclude information that could directly or indirectly identify any individual or organization. Excerpts have been lightly edited for grammar and readability.

Organization of this report

Sections 2 and 3 correspond to the two main questions put to focus group participants: (1) provide examples and insights about your experiences with structural stigma, and (2) provide guidance on what you consider to be the solutions. Section 4 provides a synopsis of the report's key findings.

Section 2. Structural Stigma: The Ghost in the Machine

Each focus group began by asking participants for an example of structural stigma. The following comments are meant as a starting point for the report's more detailed exploration of the nature of structural stigma experienced by people living with mental health problems and illness and/or with substance use. These examples highlight the range of experiences, the potential seriousness of the outcomes, and the powerlessness people feel in dealing with all forms of structural stigma.

> I experienced health-care practitioners that had mental health stigma against the patients. When admitted to hospital, the medical procedures the nurses were administering were causing pain and, in response to the patient expressing pain, the nurse responded, "If it hurts that much, that will prevent you from doing it again next time." The staff were using trauma and stigma as a deterrence, for youth specifically.

In psychiatric care, they did not tell me they were doing a suicidal watch. Cellphones were only allowed to be used in a certain area, and there is a warning that there is a repercussion. Personal storage is an issue. Every time I asked for my cellphone, everyone could not find my belongings and asked where I left it last. Not once were they able to locate my belongings. There is a closet full of things. It is disempowering. You are the ones that have my cellphone, so why can't you find it? It is very demeaning.

I experienced stigma directly from health-care practitioners when being diagnosed with an eating disorder. Staff brushed off depression by recommending, “just lose weight.” Personality disorder is stigmatized, as people with personality disorder get branded as difficult, stubborn, and manipulative. As a result, they bounce around practitioners, as no one wants to deal with that “difficult case.”

Indigenous people will not seek services as often because the interactions they will have will be negative.

I can provide the more recent experience of another mother. She was in a minor car accident and her son was with her. He refused to go to the emergency room to be checked out because he believed that the doctors would see the track marks on his arms and just think he was there looking for drugs. I know of lots of people who feel the way he did. They will not seek health care because of the stigma they face because of their drug use.

I have had ongoing issues with development and feedback of existing policies. When a new policy is developed there is a practice of organizations to put someone with lived experience in a position where it would appear they have the ability to give input that will be used. The use of a special advisory committee is inauthentic and used to simply rubber stamp a policy that has already been made.

The quiet rooms are poorly designed. It’s a room with a bed, and that is it, in which you are locked. In an emergency department, you are in another room with a security guard in front of the door and you are tied down.

I was homeless for a long time and had no identification. If you are homeless and do not have a health-care card, you do not get health care. Maybe in an emergency room, but there would still be issues.

Without a health card they will not turn you away in an emergency, but they will bill you afterward. If they know that people cannot pay, why do they bill them? It only adds to the stress those people are already under. People are less likely to go to the hospital if they know that they will be billed.

Another stressor is travelling between provinces. You can’t just get your methadone in another province; you have to pay for it. For those us of who are working on issues like this and travelling, it is a nightmare. I know some people who were attending a conference and had to pay $20 per day for their methadone because they were out of their province.

My son’s death occurred in a psychiatric hospital from an overdose. His roommate had brought in the drugs. The nurses did not notice my son dying over the course of six hours. No one noticed. They would not discuss much with me or listen to me when I told them that my son might do this. They were very much mental health nurses on a mental health ward who did not understand substance abuse or did not have any addiction skills.

Quality of care

Much research has shown systemic disparities in the diagnosis and treatment of the physical health of people with lived experience of mental health problems and illnesses and/or substance use. As the previous stories illustrate, they experience a wide range of difficulties when interacting with health-care systems.

The culture of caring is broken

An important aspect of health-care cultures is the way physical spaces and staff are organized to get the job done. It includes the range of behaviours seen as normal and acceptable: the pathways to care, clinical practices, shared ways of thinking, and patterns of communication.[3] Participants in our focus groups, based on their considerable experience with mental health care systems, described the care they received as "demeaning," "dehumanizing," "robotic," and "out of whack." It was particularly upsetting for one participant to learn that mental health care providers could be well-informed but still express discriminatory behaviours. Care routines were described as making someone feel like they were "in a correctional setting" or "a prison." Another observation was that the staff members a person deals with most, such as secretaries and administrative staff, "have the least amount of training." As one participant noted:

> The staff are nervous, it's sterile, there are many people, there is no peer support worker, and physically there are security guards.

Staff were not seen as relating to clients as people, but instead to their diagnostic label. There also seemed to be little awareness or expression of recovery principles. In this context, such principles refer to interventions that help people "move forward with hope and recovery" rather than provide medical interventions oriented to the stabilization and remission of clinical symptoms. In recent years, the notion of recovery has moved away from a narrow clinical focus that emphasizes cure to a broader understanding: as the development of new purpose and meaning in one's life in relation to lived experience of a mental health problem or illness and/or substance use. It reflects a personal journey that an individual takes toward empowerment, self-management, and meaning. It involves the right mix of treatments and supports (including supportive relationships from family, friends, and peers) along with hope.[4] The process of recovery can only work if the external environment (including health-care environments) promote personal empowerment, self-management, and inclusion.

Recovery-oriented services support individuals in their personal journeys. Unfortunately, people with lived experience often identify the culture of health-care settings as disempowering. Rather than feeling empowered, they feel patronized, humiliated, and excluded from treatment decisions, or it is assumed that they lack the capacity to be responsible for their own lives and treatment decisions. Other problems include not being given sufficient information about their illness and treatment options, prognostic negativism, and the threat of coercive treatment.[5] In their examination of recovery competencies for inpatient care, Chen and colleagues also identified the physical environment as a contributor to the undermining of recovery-oriented care: where routines and interactions are experienced as dehumanizing, discouraging, and disempowering.[6] Adopting a recovery perspective requires a complete transformation of mental health services, supports, cultures, and relationships. In contrast to a medically oriented approach, recovery-oriented systems are client and family driven,[7] and they promote person-centred care.[8]

It is worth noting that the term *recovery* has a different origin and evolution in the substance use field. Early debates pitched abstinence as the hallmark of recovery, whereas the more recent dialogues understand a range of outcomes, including harm reduction, improved social supports, social integration, and abstinence. In 2008, a recovery consensus panel appointed by the U.K. Drug Policy Commission defined the process of recovery from substance use as "characterised by voluntary-sustained control over substance use which maximises health and wellbeing and participation in the rights, roles and responsibilities of society" (p. 6).[9] Like recovery in the field of mental health care, recovery in the substance use field is person-focused and addresses wider social factors such as housing, employment, and well-being. For some, abstinence may be an important recovery goal, but for others, smaller incremental steps, such as feelings of acceptance, taking responsibility, gaining control, or improving mental health, may be more important. For still others, the most important recovery goal may be simply recognizing the need to change.[10]

In considering recovery-oriented care, participants described treatments as impersonal and too narrowly focused: broader social determinants of health such as poverty, homelessness, or unemployment were not considered.

> It is always about the prevalence of medical care and not actually buying into the fact that services must be relevant and human centred in design. Recovery/wellness looks very different for each person and, as long as they are self-directed and finding a life worth living, that should be the point. That doesn't seem to score high enough though. For example, I am in a place in my life where I don't want to take medications anymore. I am judged as being non-compliant and punished for that by not being able to access certain types of care. We really need to pull up the recovery/wellness part. The system may be able to adapt with time, but to do so they need to stop adhering to their medical/clinical protocols so rigidly.
>
> There is collusion. "Take your medication." The predominant question discussed is how to make sure these people take their medication to ensure you act in a socially constructed way. It is not just about education. The media portrays that the people taking their medication are OK.

Participants described a power differential between staff and those receiving care and an environment that was overly controlling and sometimes punitive — a situation experienced more acutely when a person is unwell and unaware of their options. Staff who were recovery oriented were easily detectable because they spent more time out of the "fishbowl."

> There is more communication with those staff who are recovery focused. Glassed-in nursing stations, fishbowl, is stigmatizing. Those recovery oriented are more likely on the floor with the patients, or those that do take part are met with the attitude, "It's not the way of doing things."

Participants also described a lack of transparency about treatments and their side-effects and a lack of communication about the processes and outcomes of care. Added to this are the poorly designed physical spaces of many facilities and the heavy use of security personnel in places such as the emergency room. Care was experienced as frightening and trauma inducing.

> If you come in the first time, explain what is happening: "this is what we're doing and why." If not, you [the client] experience a fear and trauma because you do not know what they are doing or what is next.
>
> There is a lack of transparency about willingness to discuss side-effects of medication and hospital processes of what will happen to you, how they will manage you. There is a level of communication that is missing.
>
> In my experience, being very educated and fully understanding of my life expectancy, I have been told by medical professionals I should not have got a degree as I do not have money and am a mental patient. I have seen the worst, and if staff were honest about life expectancy, as they should be, patients might get onboard if told the truth, or not, but the staff do not try. There is a lack of trust to be honest and open between mental health care

> professionals and patients. They are afraid patients will react in a certain way or have an opinion that may differ from theirs.

Diagnostic overshadowing

One form of systemic disparity that is attracting growing attention in the literature is diagnostic overshadowing. Diagnostic overshadowing occurs when a person with lived experience of a mental health problem or illness and/or substance use receives inadequate or delayed treatment for a physical condition because it is wrongly attributed to their mental ill health. In fact, persons with lived experience have higher rates of physical illness and are more likely to die prematurely, compared to members of the general population. For example, in high-income countries the life expectancy of persons living with schizophrenia is 10 to 25 years shorter than those in the general population. At least 60 per cent of these premature deaths are a result of potentially preventable natural causes, most often cardiovascular disease or cancer.[11] Yet, despite the importance of reducing premature mortality, little research has been done to examine the contributing factors and how they may interact with diagnostic or treatment bias to reduce quality of care.[12] In one qualitative study of 25 emergency department clinicians (15 nurses, two nurse practitioners, eight doctors), diagnostic overshadowing was commonly acknowledged — and its complications were often serious, ranging from irreversible side-effects to death.[13]

The reasons for diagnostic overshadowing are undoubtedly complicated. They include health-care staff that perpetuate a culture of stigma, the lack of knowledge and skills in identifying physical signs and symptoms when presented with complex cases, physical disorders that can mimic mental illnesses, and doubting the veracity of physical complaints.[14] Despite the potential complexity, Zun and Rozel[15] have described diagnostic overshadowing as one of the "cardinal dangers" of stigma. People on the receiving end cope with this problem in a variety of ways. They may avoid treatment altogether, bring someone with them to advocate on their behalf when visiting a health-care setting, or go only to settings (such as emergency departments) where their psychiatric history is unknown.[16]

Participants in this study offered several examples of diagnostic overshadowing where "medical conditions are often ignored" and triaging processes (for example, in emergency departments) place "mental illness at the bottom of the list":

> I had a common experience of having everything blamed on a mental health problem, being seen as walking mental illness.
>
> If a psychiatric condition exists and then you have a complaint about a heart or knee, these are often ignored. Other conditions are often ignored due to having a mental illness; huge stigma. There is good evidence that many patients with mental illnesses die of medical conditions not appropriately addressed, as well as side-effects of the medication, which creates cardiovascular and metabolic issues. The side-effects of medication and quality of life and the impact, there are reports of the correlation.
>
> Triaging issues are stigmatizing and the treatment of mental health problems based on a physical problem. I had an experience where I was not allowed to get treatment for binge eating until my mood disorder was controlled.
>
> In medical triage, physical comes first — harming yourself or others is put first and all medical professionals react as such. There is no help until it gets physical, proper treatment is not given until it gets to a certain point, then they give you all the support. It must be life threatening before you get help.

Substance use

People with experience of a substance use disorder, even those in recovery or on methadone maintenance, had a particularly difficult time in the health-care system. Accessing family doctors willing to support someone on methadone therapy, changing prescriptions from one geographic location to another, and finding integrated mental health and substance use care were all major barriers they faced, sometimes with grave consequences.

> My son died a number of years ago when he went off his methadone too soon. I blame this partly on the information and advice we were given about his treatment and potential relapses. We were told that we needed to practise tough love and be aware of co-dependents. I know that his death was many years ago, but I also know that stigma still exists.
>
> I had a bad experience with a nurse practitioner. I liked her and I knew that she was well informed. She sat on panels and came to hear me speak. Behind closed doors, I asked her for a safe supply for methamphetamines. She told me that she was not comfortable doing that and that I should just drink more energy drinks. I was really disappointed in her response. I am not sure what the answer is if the most informed still discriminate behind closed doors.
>
> My daughter is in recovery and is on methadone. When she was laid off from her job, she moved home with us. She was offered another position, but it meant that she would need to move. The hardest part of that was moving her methadone prescription. It was so frustrating and stressful. Everything was really up in the air until the last minute. It is not like that with other prescriptions, like blood pressure pills. Why is it so difficult for people like my daughter who also have an illness?
>
> When I think about stigma in the health-care system, a very specific example comes to mind. I have hepatitis C and a history of injection use. In 2015, I tried to get treatment for the hepatitis C, but because my liver was not scarred enough, my treatment was not covered. My workplace offered to cover the cost, but I was required to have a family doctor. The nurse at my job that was advocating for me to get treatment provided me with a list of doctors to contact, but none of them would help me because I was on methadone and had hepatitis C.
>
> [My son] was trying to find a family doctor to deal with anti-anxiety medicine. He couldn’t find one that would take him because he was still on methadone. In the end, I begged my own family physician to take him on and she did, but that is the way people on substances are treated by family physicians.
>
> I echo everything that everyone has said. I know a mother who suffered from mental health issues and addiction, as did her son. When she tried to get him help, all the health system saw was the addiction. It negated the trauma and mental health issues. The mother was very close to recovery and had her mental wellness well under control, but she was not heard because of her past with drug use. The system does not see anything but the addiction, and the people in it do not listen.
>
> Another barrier is if you are on methadone maintenance, you can’t get into residential care. Technically, you are not clean unless you go off of the methadone.
>
> I have seen people arrive for treatment and be turned away because they are under the influence. They are not even kept for a minimum amount of time to determine what their situation is. Are they addicted or just stressed out about going into treatment and had a few drinks to calm down? If they are addicted, why can’t they be referred to detox? Those in the system are robotic in the way that they deal with things. Everything is black and white. They won’t give you another date, so you have to go through the whole system again. People in the system are so afraid of losing their jobs that they don’t do what they believe is right.

Struggles of the wounded healer

A number of focus group participants wore two hats – lay and professional. They were both persons with lived experience of a mental health problem or illness and health-care providers. This gave them a unique perspective from which to examine the issues. They noted that people working in the health-care system were reluctant to disclose their own problems out of fear that it would be “professional suicide.” The health-care culture is such that providers must be resilient and tough and not have such problems. The “unspoken rule” is that health-care providers “cannot have mental health issues.”

> The culture of people who work in health care is such that they always have to be tough and strong and cannot suffer from mental illness. There is talk about how the culture is changing, people telling stories of being vulnerable as clinicians, but overall it is avoided. There is still the barrier that you could not be taken seriously. It is getting a bit better, but the vast majority would be hesitant to speak up. There are new wellness programs for those in the health-care field separate from others. Instead of addressing the stigma, they are segregated. The stigma is systemic. Each school has student affairs, but students in the medical fields are segregated. It perpetuates that someone in a health-care role must go to another specialist and cannot go to the normal resources for help.
>
> Mental illness can make you a better nurse and more empathetic to people going through pain. I sought action to lessen my course load, as I was worried school would deteriorate my mental wellness. The university denied lowering workload and responded, “Nursing is not for people with mental health issues.” It was not until legal action was threatened that the university accepted having a lessened workload due to mental health.
>
> Where do mental health practitioners get support? [The province] has a small mental health community. When you need to turn to someone for support, there is a conflict of interest, as the circles are small. To get peer support, to use the service, and then to go back and use that industry for employment, there is an issue with them knowing who you are, expressing stories, and people you have connected with. It is hard to be honest with current experiences, as you are seen as an advocate.
>
> It’s difficult having a working relationship within the industry and because of this you cannot seek help, specifically in peer support and being on top of giving support to those struggling and needing help. Yes, I am helping you help others, but I am still struggling. I cannot go back to these people because they know me. . . . The idea of a wounded healer, it is helpful for therapeutic rapport and normalizing that conversation. There is benefit in pushing through; it puts a lot of onus on the self.

Commentary

These stories paint a grim picture of the nature and effects of structural stigma in health-care settings, with outcomes that include disempowerment, disenfranchisement, dehumanization, treatment avoidance, disability, and even death. While it is not clear whether these particular examples reflect the exact day-to-day experiences of all people, the research is clear: considerable stigma exists in health-care settings.[17] Indeed, that is one reason why the MHCC’s Opening Minds program has deliberately targeted health-care providers and health-care settings for its anti-stigma activities.[18]

Section 3. Suggested Solutions

Focus group participants were asked to comment on potential solutions to the problems they had raised concerning structural stigma in health-care settings, and there was no shortage of ideas for how to create systemic change. The following suggestions were offered.

Legislative and policy change

Legislation to address discrimination against mental illnesses has been a notable feature of the legal landscape over the last several decades, both in Canada and globally. The United Nations Convention on the Rights of Persons with Disabilities has provided added emphasis on structural equity in health and social settings.[19] In addition to legislation, there must be sufficient avenues of redress for people who consider their rights to have been abused.[20]

Legislative and policy change was described as a "go-to for health-care changes." In addition to targeting and educating legislators and those in relevant policy positions, participants also considered the need for greater input from people with lived experience in policy development.

> The patient advocate and the health-care advocate must be knowledgeable and competent — meaning [they] have lived experience — about the subject.
>
> The civil rights movement, for example, how do we create a social movement? What is required is people with lived experience to advocate for equity, equality, and a legislative approach. We must be very mindful in communicating to legislative people what is the reality, what does the need look like, why and how practical can you make it? You cannot see a mental illness in the same way you can someone with a physical disability.
>
> Somehow make things easier to enforce. There needs to be a standard for protection no matter where you live in the country.
>
> It begins with the interview process. People with lived experience should be sitting in on those interviews. The staff are there to serve those with lived experience, and they should provide input in developing the interview questions.
>
> There is a need for awareness that the policies being developed by the organization are not including a recovery philosophy that can reduce relapse.
>
> The awareness must be embedded in the power structure of the system in some way. There must an incentive created to follow best practice.

Education and support for health-care providers

Participants frequently identified having a more comprehensive education for health- and mental health care providers as an important fix. This enhanced education is needed for both students in post-secondary institutions and for those already in the field (through professional development). Individuals with lived experience of substance use emphasized the need for harm reduction approaches. Culturally safe care, including trauma-informed care and stigma reduction programs, were also considered essential for front-line providers. In addition, participants identified a need for more of a "customer service mentality," particularly among front-line and administrative staff.

> Residents and medical students should have more than six hours of mental health care education. The mental side is very important. Mental health is not a big a part of the education.
>
> I suggest to start with medical education and build an environment amongst peers to speak about struggles, learn more about illness experiences, and how identity factors tie in. In crisis situations, there is a need for how to assess the competency of a patient. From anecdotal experience, they must err on the side of caution to mitigate risk, more training for how to make decisions on patients' competency. You can be put on involuntary hospitalization; there needs to be more training.
>
> I suggest better continued learning. More training for those in positions who may be rooted in their practices; they influence new people in training.
>
> To change the system, you must get to them before they get to be a part of the system. More education.
>
> We must change the training and perspectives of family doctors. How do we change these people who have been trained to see addiction as a moral failure and a criminal issue, not a health issue? They only receive two days training in medical school about addiction. The education piece is so important, especially at the youth level. It needs to include lived experiences. We need to use the safe sex model to promote safe use.
>
> Speaking with people who have gone through the hospital system – have conversations with people which have gone through it. Facilitate casual conversations to understand experience.

Recovery-oriented care

The notion of recovery has dominated mental health policy discussions for some time now.[21] However, there is still some confusion over what recovery means in connection with mental illnesses. In that context, recovery is used to describe something individuals experience as they manage their lives, something mental health services promote, and something systems facilitate. To help clarify the recovery discourse around mental illnesses, Jacobson and Greenley[22] have offered a conceptual model, in which recovery refers to both internal conditions (such as attitudes, experiences, and processes of change) and external conditions (such as practices, policies, and circumstances that may facilitate or hinder personal growth). The key conditions for realizing the recovery process are

- hope (a belief that recovery is possible)
- healing (defining the self apart from the illness and gaining control)
- empowerment (a sense of autonomy, a willingness to take risks, and personal responsibility)
- connection (reconnecting with others and developing new meaningful roles in the world).

Professionals who view recovery as a return to normal health often resist this notion of recovery because they see it as unrealistic. Yet, they may not know how to help people with mental illnesses recover their sense of self, self-esteem, and self-respect. As we learned in the previous section, health-care services can be experienced as uncaring, disempowering, paternalistic, and stigmatizing.

In this context, training mental health care professionals for recovery-oriented care was seen as a high priority. Because participants thought mental health staff were often unaware of recovery principles, they saw a need to replace the current medical disability paradigm with a broader model based on the social determinants of health. Doing so would help promote a positive culture of healing, where professionals and their clients are empowered and engaged.

> [Organization name] needs to address social determinants of mental health. It is not just more medicine. There needs to be just as much parity around the social aspects of what helps people to get better and stay better longer.
>
> It should be a social model. There is little talk about food and nutrition to support mental health. If you want a special diet, you must qualify under certain, restricted criteria. Many suffer from lack of nutrition. Employment and housing are all connected.
>
> This is for all departments; the recovery concept is not just for medicine but anywhere a person with lived experience with mental illness makes contact with government support systems.
>
> What are the concerns of the service providers with recovery philosophy, and how is the crisis response centre to go forward with recovery philosophy? This will require a peer to be there to implement reform.
>
> Trained psychiatric nurses need aptitude around recovery-oriented principles.

Culturally sensitive care

In the second focus group, which was more ethnically and culturally diverse than the other two, members had a particularly animated discussion about the importance of patient-centred, culturally sensitive care, including knowledge of intergenerational trauma and trauma-informed care. Culturally sensitive care takes into account the views of its culturally diverse clients, not only the views of health-care professionals, and is reflected in health-care policies and practices that convey respect for clients' cultures. It has been described as care offered in such a way that it is relevant to clients' needs and expectations and responds appropriately to their attitudes, feelings, and circumstances.[23,24]

Focus group participants thought there should be toolkits to help mental health and health-care providers understand the nature and meaning of mental health problems and illnesses in diverse cultures — a dictionary of sorts to provide a snapshot for each cultural community and the language that would be considered demeaning, blaming, or shaming.

> Toolkits should be tailored to the specific clients they are being used with. There is a lack of outreach to families, and it can be toxic. It is hard to educate families of ethnic backgrounds who cannot relate to the educator; there is no conviction, as they do not share the same experiences. Outreach health-care practitioners would be better received if they possessed more relatability; families would be more receptive. The use of specific language in the approach is an important component to making outreach more receptive. Using words like suicide holds negative connotations in itself.
>
> The government of [name] trains health-care providers on intergenerational trauma; health-care providers coming from out of territory must go through this. This improves the stigma associated with Inuit having mental health issues. . . . It makes it easier to see the bigger picture of why someone is struggling, and cultural competency is important for Indigenous communities.
>
> Cultural competency directly affects stigma. Cultural relevance will vary across Canada.

Peer support

Peer support is considered a key part of recovery-oriented care because it focuses on strengths and recovery — a person's positive aspects and the ability to function effectively in social roles that are meaningful to them. The literature supports the idea that peer support workers may be more successful than professionally trained mental health workers in promoting hope, a belief in recovery, empowerment, a positive self-concept, and social inclusion. Employment for peer support workers offers financial benefits, plus the added advantage of promoting their own recovery (by having a valued social role).[25] In addition, there is evidence that peer support workers teach non-peer staff members about recovery and recovery-oriented care,[26] and so they are key drivers of cultural change.

Peer support roles have been introduced into a variety of mental health organizations worldwide, with peer workers participating in a broad range of functions within them. What is considered distinctive about peer support is that its set of values stands juxtaposed to typical mainstream clinical practices, which emphasize medical disability.[27]

In addition to promoting recovery for people with serious mental illnesses, focus group participants thought peer support workers embedded in health-care organizations could provoke positive cultural change. But, there was also recognition that the way peer support was being embedded in agencies required greater scrutiny.

> Peer support workers who are embedded in agencies are changing those cultures. They are modelling what recovery can be. They provide additional skill sets that can help to break the stigma.
>
> There has been a lot of work done in peer support provisions, but there is much more to do: the whole part about embedding peer support workers in agencies to help change culture, the whole systemic piece about policies and procedures. We need more training to help us with training certified people. The way that peer support is oriented into agencies needs to be looked at more closely.
>
> We need to fund drug user groups and grassroots peer support. The funding should be without stipulations. We know what needs to be done. We see things that need to happen and work really hard to make them happen. We need help. We don't have enough money or resources.

Recovery-oriented metrics

Because a larger goal of the MHCC's structural stigma project (of which this study is a part) was to develop an audit tool that organizations could use to monitor progress on eliminating it, participants were asked about potential metrics that could be used. There was clear agreement that a metric focused on recovery would be important for promoting social equity in health care for people with mental health problems and illnesses. Because "people who are struggling do not have a voice in what they need," such a metric would highlight problem areas and give organizations a way to gauge progress and target educational opportunities for staff members. Some thought the metric should be directly tied to funding; for example, with surveys that enable clients to describe how they felt going through the system. "Once the money says you need to change, change happens." Items that were flagged as important included wait times, deaths by suicide, and levels of peer support. Whatever the approach, participants strongly agreed that it would require considerable input from people with lived experience so as to reflect outcomes that are important to them.

> There should be accreditation or audit tools to assess sensitivity towards mental health issues. Another part is you are put on a spectrum of who is the best or worst hospital; it's an incentive to strive for better.
>
> But how to make this better? Rely on outcomes, evaluations, and there are challenges. Should be measured on clients' goals for their life. Progressing in a career in personal life would be an outcome that evaluations should be measured against. The system is not tracking or evaluating such; it should be about the outcomes as described by the patient. New programs are evaluating the desired outcomes of patients, but these people are not accountable to their data. If they prepare reports, they are not required to make them public.
>
> An audit tool for organizations to monitor their behaviour would require a lot of client buy-in.
>
> If a hospital had a questionnaire or template that would make the things that identified your recovery-oriented goals, where the employee could check "good" and comment "needs more work," excellent. If this was done in an empowering way, you can prepare learning sessions, modules, do be better at recovery-oriented services.
>
> Internal audits have to reach beyond the internal; it must go to the external, to those who have been affected. We are doing hospital surveys, and there is a reluctance of what is happening inside the service for fear of loss, even if they are anonymous. There is an association with disclosure and having a repercussion later on. Community meetings are supposed to be for patients, but comments are shot down due to confidentiality. How can you breach your own confidentiality?
>
> There is a need to figure out how to assess quality in a positive way, which is not demeaning to staff, as their concerns cannot be dismissed.

Section 4. Synopsis of Key Findings

This qualitative study was part of a larger structural stigma project undertaken by the MHCC. In this report, structural stigma refers to the accumulated activities of social structures and organizations that create and maintain social inequalities (deliberately or inadvertently) as they affect persons living with mental health problems and illnesses and/or with lived and living experience of substance use. The purpose of this project was to learn about individual experiences of structural stigma in health-care settings. More specifically, it sought to

- gain a better understanding of the potential role of organizational practices in creating and maintaining structural stigma
- identify constructs that could inform the development of a generic framework to depict the nature of structural stigma
- inform the development of an audit tool that could be used to assess and monitor the occurrence of structural stigma.

Qualitative data were collected from a total of 20 individuals in three focus group sessions (about 90 minutes each). The 20 participants represented a broad cross-section of people in Canada who had encountered structural stigma due to their lived experience. They included youths, Indigenous peoples, mental health advocates, clinical care workers, and peer support workers, who were recruited from MHCC and partner advisory groups. An external firm specializing in transcription captured the verbatim focus group conversations, which formed the basis of the qualitative analysis. The data collection procedures received clearance from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

In terms of the focus groups themselves, participants did not have any difficulty identifying examples of structural stigma in health-care settings. Indeed, there was a broad range of experiences. Many centred on the poor quality of care received by people living with mental health problems and illnesses and/or substance use, where the culture of caring appeared to be broken. This poor quality included physical and social spaces that were experienced as disempowering as well as a range of behaviours by clinical staff that diminished self-esteem, personhood, and recovery. Participants blamed such experiences on the narrow clinical focus toward diagnostic labels and symptom reduction, which takes precedence over a broader social approach that includes recovery principles such as empowerment, self-management, and meaning making. They were acutely aware of the power differential between staff and clients and the overly controlling and sometimes punitive approaches used in the treatment encounter. In addition to a lack of transparency about treatments and medication side-effects, there was inattention to clients’ physical health. Diagnostic overshadowing was frequently identified as the cause of inadequate or delayed treatment for a medical condition. Persons with lived and living experience of substance use felt particularly stigmatized in health-care systems (something that can result in substantial levels of disability and premature death). The significant problems identified were an inconsistency of care across geographic regions (e.g., when a person moves and needs a methadone prescription), inadequate access to family physicians, and stigma surrounding methadone treatments. The lack of culturally safe and sensitive care and the compounding impacts experienced by people with multiple stigmatized social identities was also discussed. Several participants were themselves clinical care providers and wore an additional “wounded healer” hat. While they considered their unique perspective as something that allowed them to be more empathetic, the unspoken rule of health-care cultures is that health-care providers cannot have mental health problems and illnesses.

These stories paint a grim picture: the detrimental effects of structural stigma on mental health and substance use clients in the health and mental health systems have significant psychosocial and health impacts. One thing that cannot be known from a study of this nature is how often structural stigma occurs. We only know that it does occur and manifests in myriad ways. Given the significance of the outcomes our participants experienced, these results strongly support the development of an audit tool (and other tools and measures) that organizations could use to examine sources of structural stigma, monitor progress over time, and help target educational interventions for staff. They also point to other potential avenues of redress, including changes to legislation and policies; education and support for health-care providers; promotion of recovery-oriented care; person-centred, culturally sensitive care; and greater access to peer support.

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