

“Do I want to live like this?”

Albertans describe depression that is unresolved after the use of
two or more antidepressant agents

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PROJECT OVERVIEW

Depressive Disorders are among the most commonly diagnosed mental illness. **An estimated one in every four Canadians have a degree of depression severe enough to need treatment at some time in his or her life.** Depression may affect someone once or many times in their life or it may be chronic. There are three major types of depression: **major depressive disorder, persistent depressive disorder (dysthymia) and bipolar disorder.** This project focuses on major depressive disorder; specifically Albertans whose depression is unresolved after the use of two or more antidepressant agents. The information collected by this project contributed to a greater understanding of individuals living with, or caring for someone living with, unresolved depression. The findings will be used to support Albertans impacted by depression wherein existing treatment options have not provided relief.

RESEARCH APPROACH

Canadian Mental Health Association (CMHA), Alberta Division conducted a survey and follow up focus groups on the topic of depression that is unresolved after the use of two or more antidepressant agents. The aim was to understand the impact of depression on everyday life and explore people's experience with medication and other treatment options. Participants were adults (18+) who identified as someone with depression and had tried, or are trying, two or more antidepressant medications but have continuous or unresolved depressive symptoms (a formal diagnosis was not required). Sixteen individuals completed the survey

and five partially completed the survey. Participants aged from 22 to 62, approximately half of whom received a diagnosis of depression over ten years ago (43.8%, n=7/16). The project also included five focus groups – two in Calgary, two in Edmonton and one in Red Deer (n = 9).

The content of this report is credited to the participants and recognizes their courage in sharing their stories to help improve the lives of all Albertans living with depression. The synthesis integrates both quantitative and qualitative responses to provide a fuller picture of the experience of living with unresolved depression.

UNDERSTANDING THE ‘QUIET EPIDEMIC’

When participants were asked how depression impacts their life, one participant said, “how does it not?” Other participants echoed this with specific references to sleep, appetite, mood, relationships, exercise, work and the ability to do the activities they used to enjoy. Another participant emphasized even the tasks of daily life -getting out of bed, getting ready, preparing meals, tidying the house – ‘can be insurmountable.’ Participants also reported feeling apathetic and spoke of a “darkness” they felt was always present. In the pre-survey, participants unanimously reported experiencing feeling tired or having little energy; little interest or pleasure in doing things; feeling down, apathetic or hopeless; trouble falling or staying asleep or sleeping too much; difficulty concentrating; and poor

SPOON THEORY

The Spoon Theory is a disability metaphor and a new way of explaining the reduced amount of energy available for activities of living and productive tasks that may result from disability or chronic illness. “Spoons” are a visual representation used as a unit or measure to quantify how much energy a person has throughout a given day. Each activity requires a given number of spoons, which will only be replaced as the person “recharges” through rest. A person who runs out of spoons has no choice but to rest until their spoons are replenished.

- Focus Group Participant

appetite or overeating. All but one participant also reported ‘feeling bad about yourself – or having feelings of failure, letting yourself or others down.’

Before diagnosis, participants reported ‘negative coping’ strategies like self-harm, alcohol abuse, abusing pain medications and doing drugs. Some individuals noted they cried a lot and isolated themselves, a few reported suicidal thoughts, while others consciously hid their struggles from those around them.

Participants spoke about their beliefs in how family, friends, and society view them. They reported being labeled as “broken” or being told to “just go get fixed.” Even when trying to be helpful, family and friends were often a source of stress for the participants. One participant said when family told them “you’re doing so well,” they thought “no I am just getting better at hiding it.” Family, friends or co-workers make comments like “just breathe,” “think happy thoughts,” or “snap out of it.” Participants

shared this evokes a sense of frustration, anger and sadness and only further demonstrates to them how much others don't understand what they're going through and are tired of trying to explain what the disease is like for them. Participants described mental illness as a "quiet epidemic" and the healthcare system doesn't have sufficient supports or treatment options for them and their loved ones.

Dialogue on social supports also included how participants viewed themselves. For instance, "I don't want to be around me, so how can I expect that of others?" Some individuals noted feelings of self-loathing. Several participants expressed how they've isolated themselves to avoid noise, crowds and social interactions like shopping or going out with friends. Others acknowledged screening phone calls or fabricating addictions or dietary restrictions to avoid attending social events. Participants stated having supportive individuals who were willing to be present or to 'help with basic daily activities' would be useful.

Despite campaigns to reduce stigma surrounding mental illness, participants reported feeling they had to hide their condition, particularly at work. Other participants expressed working wasn't within their ability at the moment, while others said it was essential because of finances or the medical coverage they gained from working.

The most common challenge people articulated about living with depression was related to the financial impact. Those who are not working are struggling to live off savings or disability payments. Individuals who are on a leave of absence from work are technically still employed, which can limit their access to programs, supports and resources from the government. Participants who are working reported pressure to increase hours, stress from feeling the need to hide their condition, adverse impacts from disclosing their illness or concerns, and regression in their ability to cope with depression. The high out-of-pocket treatment costs add to participants' financial stress. In the survey, 86.7% (n=13/15) reported experiencing financial difficulties since receiving their diagnosis.

MANAGING, MEDICATING AND MEANDERING

Participants reported trying multiple treatment options in hopes of managing their disorder, sometimes trying several treatments simultaneously. Participants noted there are many barriers to accessing appropriate care in the public system, such as long wait times and appointments which may require substantial travel. Furthermore, provider or system availability and preferences seem to be the core factor in scheduling appointments, instead of when the participant would have preferred or been able to attend. For example, participants reported limited day-time appointment options and no evening appointments.

One essential struggle participants emphasized was difficulty accessing private mental health care services.

Forty-seven percent of participants (n=7/15) reported a hospital admission for their depression. The amount of lifetime total in the hospital reported ranged from one week to approximately three years – depending on the age of the participant and the timing of their diagnosis. Most participants reported receiving information on treatment options from a family physician (87.5%, n=14), psychiatrist (87.5%, n=14) or a counsellor (68.8%, n=11).

All participants had tried some medications. Most individuals reported severe side effects including memory loss, a worsening of symptoms or complications of other conditions that they have (e.g., depression medication increased anxiety issues). For some individuals the medications had no impact. At best, one participant reported their current combination of drugs made them "numb." Medication-related side effects impact the overall quality of life and willingness and ability to seek new treatments. In the survey, the most frequently reported medications were Bupropion (brand: Wellbutrin) and Venlafaxine (brand: Effexor). One participant reported trying up to 23 different prescription drugs with no success. Many said they would be willing to continue to try new medications in the hopes of finding one that works.

The public perception of managing mental illness through walking or exercise has created a new challenge for participants as their family and friends encourage them to exercise as a panacea for depression. Participants spoke of wanting successful treatment solutions, but lamented that there is no magic fix.

Individuals in the focus groups relayed they have tried many treatments with mixed or poor results. Some said they weren't fully aware of the risks and efficacy related to electroconvulsive therapy (ECT) and they felt pressured into it by health care providers. In particular, many participants noted to decline ECT would result in being labeled a "difficult" or "non-compliant" patient. Some participants reported little change to their condition since their diagnosis, which leads to higher levels of suicidal ideation.

Participants revealed the myriad of health care providers they see to try to manage their depression typically do not communicate with one another. As a result of the lack of inter-

professional communication, there is an increased burden on patients to find and manage their own care team. In the focus groups, participants shared there seem to be different types and varying quality of treatments offered across the province – particularly between rural and urban settings. Some participants shared their health care providers did not seem to be up to date with the latest research on depression and did not have a clear set of recommended treatment options. Many participants have other diagnoses and some reported poor interactions between the treatments for the various conditions. Participants also acknowledged feeling vulnerable and trying to find answers on their own as the treatments they are receiving were not helpful.

SUMMARY AND SUGGESTIONS

Participants reported their diagnosis and available treatment options severely impact their quality of life. The following table provides an overview of the stakeholder input on the challenges related to living with depression and how those manifest at either a healthcare and government level or more broadly in society (e.g., supports).

TABLE 1: SUMMARY OF PARTICIPANT-REPORTED CHALLENGES

Depression-related Challenges	Government and Healthcare	Society
Avoidance behaviors	Limited funded options for mental health treatments and supports leading to high out of pocket expenses	Stigma
'Dark' feelings	Limited disability funding supports	While awareness is improving, still little public knowledge of what its like to live with it
Feeling like a mask is needed to survive in society	Limited patient choice in appointment scheduling	Family and friends don' t know how to help – resources for them
Ability to work	Medication side effects can sometimes be worse than the illness– memory loss, complications with comorbidity treatments	Advice from loved ones can cause frustration and pain, e.g., "you're doing so well" or "snap out of it."
Apathy	Declining a treatment option viewed as "non-compliant."	Co-workers ostracizing them; feeling they need to hide diagnosis from colleagues
Self-loathing – restricts relationships and social participation	Not always informed of treatment efficacy or side effects	Pressure to return to work at the expense of participants' wellness

Having unresolved depression was like "getting a terminal illness diagnosis."	Complexity – managing multiple conditions	Perception that there' s no hope for recovery
Suicidal thoughts "do I want to live like this"	Poor communication between providers	

Participants gave their time and shared their journey for this research. Based on their personal experiences the following areas for improvement were identified:

BETTER SYSTEM COVERAGE

There are limited treatment options through the public system. Barriers to receiving these treatments include wait times, appointment scheduling and service locations. Nearly all participants (86.7%) reported experiencing financial difficulties since their diagnosis. In the focus groups, high out-of-pocket treatment costs and gaps in social funding support were the main reasons identified for financial distress. Expanding the publicly-funded treatment options would reduce the out-of-pocket expense and improve participants' supports.

BETTER SYSTEM INTEGRATION

Participants remarked they are being forced to manage their care and ensure information gets to each of their care providers. Participants reported poor or no communication between their health care team and felt like this is another burden on them. They also noted there are differences in the breadth, depth and availability of treatment options offered across the province and some providers do not have current information about the disease.

RESOURCES

Participants noted there is limited information, tools or support for both patients and their caregivers and social supports. In the pre-focus group survey, participants indicated a preference for receiving health information on websites (93.8%), through webinars and

public education events (43.8% each) and in pamphlets or podcasts (37.5% each). For many, the flexibility of the virtual options means they are more likely to participate. Participants spoke of how family and friends don't know what support is helpful and therefore ask the participant what they need or step away from the relationship. Better education and communication resources for individuals who have a loved one living with depression could help improve the progressive isolation often experienced by Albertans living with unresolved depression.

FINAL THOUGHTS

More than 930,000 Albertans consult physicians for addiction and mental health-related concerns each year and more than 500,000 Albertans fill antidepressant prescriptions in the course of their treatment. The experiences shared by the focus group participants have added depth to our understanding of the challenges faced by Albertans who are impacted by depression wherein existing treatment options have not provided relief.

While the number of participants in focus groups was relatively small, the feedback is remarkably unified concerning impacts related to the quality of life, economic challenges, systemic barriers and resource limitations. The extent of the agreement is perhaps the most alarming discovery of this study. Failed drug treatments can create personal jeopardy and relational challenges that are difficult to overcome.

There is also a need for continued advocacy efforts for equity in publicly-funded supports related to health, including mental health. Affordable, equitable and timely access to the full spectrum of psychological support is critical for individuals when medication alone does not resolve depression.

It is pivotal to improve information sharing between health care providers, community supports and the matrix of systems individuals with depression are required to access over the course of their illness. Continuity of care can help decrease patients stress associated repeating traumatic experiences again and again with each new provider. Support systems that consider the needs of the whole person and not just individual segments are essential examples of ways that integration and enhanced information-sharing would benefit individuals living with major depression.

Providing education and support to families on what it means to have depression or live with someone suffering from major depression disorder is crucial to enhancing the quality of life of the individual. It is also vital to ensure appropriate care for caregivers as this may improve the quality of lives of Albertans living with depression and their loved ones.

Finally, we recognize individuals living with depression report an overall lack of resources and options to support their recovery and inform themselves and their families. Virtual and in-person supports are required to create a diversity of pathways for learning about depression and building information and resource pathways which are accessible to individuals, families and communities.

The wisdom and bravery of the focus group participants have begun to shed light on the acute needs of Albertans living with major depressive disorder that is unresolved with existing treatment options. Some of these identified approaches may exist elsewhere in Canada or the world and require dedicated implementation support to bring them to Alberta. Others need multi-sectoral collaborative efforts to overcome bias and stigma, entrenched clinical practice and other systems-level challenges. This project has acutely focused attention on the challenges that impact the quality of life of Albertans with unresolved depression and the importance of a comprehensive approach to addressing them.

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For more information, please contact:

Canadian Mental Health Association, Alberta Division

780-482-6576

alberta@cmha.ab.ca