


Unmet Needs in the Treatment of Schizophrenia:

A cross-disciplinary,
pan-Canadian
perspective

DISCLOSURE: The meeting leading to this expert consensus report was sponsored by Otsuka Canada Pharmaceutical Inc. and Lundbeck Canada Inc. This report represents a summary of the discussions that took place during the meeting. Discussions were solely based on scientific evidence and expert opinion. Discussions and recommendations presented during the meeting were supported by the company, and all multidisciplinary participants were independent experts in their respective fields. Medical writing was provided by Myelin & Associates and funded by Otsuka Canada Pharmaceutical Inc. and Lundbeck Canada Inc.



INTRODUCTION

Schizophrenia spectrum disorder (SSD), which includes schizophrenia and schizoaffective disorder, is a constellation of complex, serious, and lifelong conditions that require management for the duration of a person's life. SSD is defined by abnormalities in the perception or expression of reality, impacting a person's cognition, emotion, and behaviour.^{1,2}

The burden of SSD is significant for individuals, their families, and society.^{3,4} People with schizophrenia are likely to die earlier, by 15–20 years.⁵ Substance use is 3x higher, and suicide rates are 20x higher than in the general population, particularly during the early stages of schizophrenia.^{6,7} Further, people with SSD are at higher risk of comorbid medical conditions, such as heart disease and diabetes, which are underdetected and undertreated.⁵

Poorly controlled or untreated SSD can lead to severe and enduring medical, social, and functional challenges, including frequent hospitalizations, job loss, homelessness, and reduced social integration.^{3,8} Early recognition and treatment of symptoms significantly increase the likelihood of individuals returning to their baseline functioning and achieving better long-term outcomes.^{3,4} People with SSD often experience cycles of relapse, marked by acute symptoms, and remission, when symptoms are

better controlled.⁹ Relapses can be profoundly distressing, contributing to a decline in outcomes and increased risk of mortality.^{2,8,10}

A pan-Canadian panel of multidisciplinary experts in schizophrenia care convened to discuss the unmet needs of people living with schizophrenia — and those who care for them — and to identify the barriers that prevent them from leading a life filled with wellness, purpose, and hope. Psychiatrists, nurse practitioners, pharmacists, support organizations, and former government payors were represented.

The panellists engaged in a dynamic discussion, offering diverse perspectives from across the schizophrenia community. Their dialogue highlighted the significant burden of the disease and the existing gaps in care.

This summary captures the panel's key insights, emphasizing the need to optimize medical care, enhance access to supports, and shift perceptions surrounding

this life-changing condition. A unified, pan-Canadian approach is essential to:

- Support patients and families in addressing the functional recovery needs of individuals with schizophrenia.
- Develop national guidelines and quality standards to measure and guide care.
- Educate clinicians and the public to reduce stigma associated with schizophrenia.
- Establish a national patient navigation service to strengthen safety nets and improve access to care.
- Implement a national peer-support program for clinicians to enhance quality of care and provide education on baseline healthcare needs.
- Create clear pathways for people with schizophrenia to achieve and sustain a fulfilling, normal life.

People with schizophrenia need help to receive optimal health care

PREVENTING RELAPSE IS A PRIORITY

Relapse negatively impacts brain volume,^{11,12} and every successive relapse can further reduce the levels of baseline functioning. Multiple relapses may also reduce the response to therapy and increase the time to remission.^{10–12}

Relapse impacts patients' ability to work or be in school; jeopardizes relationships; increases the involvement of first responders and rates of involuntary hospitalization; and can elevate the risk of suicide, substance use, homelessness, or mortality.^{2,9,10}

Nonadherence, where a patient does not consistently take their prescribed antipsychotic medication, is a consistent issue in schizophrenia treatment, as it dramatically raises the likelihood of relapse, rehospitalization, poor quality of life, and healthcare costs.^{2,10,13,14}

Nonadherence can be higher during times of transition, such as inpatient to outpatient care.¹⁴

PATIENTS ARE NOT BEING TREATED WITH THE AVAILABLE THERAPIES

Schizophrenia can be treated with a combination of antipsychotic medication, education, primary care and hospital-based services, and community supports.^{3,12,17,18} Some medications could be prescribed less frequently due to barriers to access, perceptions of coercion, or the impact of monitoring.⁵ A collaborative initiation of treatment was discussed to be an important aspect of ensuring patients begin their therapeutic journey and adhere to medication.

Barriers to accessing medication are also a challenge.¹⁹ The cost of medications can be prohibitive in some

“Our patients are human beings who may kill themselves if they aren’t treated.”

regions, and systems' criteria may require relapse before access to certain therapies can be provided. Even administration fees can be out of reach for some patients, and processes for gaining financial support can be onerous. Often, clinicians are required to complete extensive paperwork in order to prescribe certain medications or are not able to prescribe medications that aren't included in the formulary.

Panellists felt that patients deserve access to personalized treatment options that best suit their unique needs and personal goals.¹³

Pharmacological treatment is often complemented by nonpharmacological approaches, including family intervention, psychosocial support, motivational interviewing, and cognitive behavioral therapy.^{13,18} However, the complexity and side effects of medication often make it the primary focus of treatment, leaving nonpharmacological support less accessible to many patients. To increase the chances of functional recovery, a combination of medication and other types of support is seen as the best approach to optimize medication adherence, increase patient acceptance of interventions, and build insight.

BASIC HEALTHCARE IS OVERLOOKED

Schizophrenia is associated with complications and comorbidities that can contribute to poor health outcomes.

Baseline medical care, such as cardiovascular monitoring or screening for diabetes, is often overlooked due to patient behaviours, more focus on psychotic symptoms, less access to health care, and clinician attitude.^{5,20}

Further, medications used in the treatment of schizophrenia are associated with a variety of significant comorbid conditions and side effects, which can impact patient adherence and overall health.^{13,21} Anticipation and management of side effects were considered to improve patient wellness and reduce the likelihood of nonadherence.

LACK OF NATIONAL GUIDELINES AND STANDARDS

Efforts to standardize care are underway at the provincial and territorial levels; however, each region employs a distinct approach to managing schizophrenia.³ A unified, pan-Canadian, evidence-based strategy is needed to enhance patient care across the country.

While organizations such as the Canadian Consortium for Early Intervention in Psychosis (CCEIP) have been working for many years to improve care and offer guidance for clinicians across Canada, implementing quality standards into workflow continues to be a focus. Integrating psychiatry more fully into the use of electronic medical records

and clinical order sets would offer measurable outcomes and data to ensure quality standards are being

met.²² Additionally, the development of a national peer-support network and updated clinical guidelines were

proposed to better support both clinicians and patients in achieving improved outcomes.³

People with schizophrenia need hope that they can have a normal life

MOVING TOWARD A FUNCTIONAL RECOVERY PARADIGM AND SHARED GOALS

Symptoms can affect patients' ability to function well at home, school, or work and interact with friends or family. Many clinicians associate a lack of symptoms, primarily positive symptoms, as the marker of effective treatment.^{17,23} However, patients are often willing to tolerate a certain level or type of symptom and still have a normal life. There is a shift toward "functional recovery," where a person experiences stabilized symptoms without relapse for at least two years, lives independently, participates in society, and engages in social relationships.^{17,23}

All panellists discussed the importance of including patient goals and the family's perspective in evaluating options for the management of schizophrenia. Clinicians need to truly understand what matters to patients and families and create treatment plans to help achieve those goals.¹⁰

Empowering people with schizophrenia to meet their goals can lead to a satisfying, productive, and independent life. Shared decision making tools, such as the [CCEIP's Functional Recovery tool](#), and motivational

"We want to help people to move beyond symptom management and to live beyond the limitations of schizophrenia with whole purpose and meaning."

interviewing can be used to collaboratively create a management plan that encompasses the goals of both the patient and the clinician.^{24,25}

STIGMA SURROUNDING SCHIZOPHRENIA IS NEGATIVE

Panellists shared that receiving a diagnosis of schizophrenia can elicit intense feelings of hopelessness and grief for people and their families. The perceptions of this disorder are of fear, violence, illness, substance use, homelessness, hopelessness, disconnection, loss, and coercion, and these perceptions have not substantially improved over time. People are scared of schizophrenia. This stigma often interferes with patients' ability to maintain close relationships with family and friends and function within

social settings. It dissuades people in early phase SSD from seeking help, which can impact their outcomes.²⁰

Further, clinicians are often uncertain or hesitant to provide care, preferring to rely on psychiatrists, who do not have capacity for the full spectrum of care that this population requires.²⁶ Indeed, panellists discussed the perceptions that people with schizophrenia can't be helped, or worse, are not deserving of help.²⁰ These people need hope. With appropriate management and support, people with schizophrenia can live a normal life, whatever that means to them.²⁴

Parallels were drawn between different perceptions of treatment with conditions such as cancer, diabetes, and heart disease in comparison to schizophrenia. For example, the use of needles is not questioned in other disciplines like they are in psychiatry.²⁷ Educational programs are needed to highlight stories of people with schizophrenia who are well and living fulfilling lives. Such programs can also help clinicians enhance their approach toward the care of these individuals.²⁰

"How do I live with this brain,
in this body, within this community?"

People with schizophrenia need better access to care

NOT ENOUGH RESOURCES TO MEET THE NEEDS OF PATIENTS

Health system resources lack capacity to meet the needs of patients, leading to insufficient care, long wait times, and an overreliance on emergency care.^{28,29} By ensuring people with schizophrenia stay well, the trickle-down effects on healthcare systems can be significant — reducing hospitalizations, police interactions, suicide, and comorbid conditions.

NAVIGATING THE SYSTEM IS CHALLENGING

Patients and caregivers often need to advocate for themselves to ensure their needs are met. This involves navigating complex and cumbersome procedures and hurdles, such as those related to medication administration and coverage, resources, or housing. Many experience high levels of anxiety when it comes to navigating health systems. Patient-support organizations can help to bridge this gap, but resources are limited and operate within a provincial context that may not have a counterpart in other regions.³⁰

Clinicians also find many of the policies and procedures to be challenging. Referral patterns and medical-legal processes vary greatly by location.³⁰ Panellists shared that paperwork and complex criteria have been barriers to providing access to appropriate medications, supports, and care for patients. While patient-support programs have offered clinician support for individual therapeutics, creation of a national patient-support program would help address the needs of patients and clinicians. Community

“Barriers to care further marginalize an already disadvantaged group.”

treatment orders can be highly effective for patients who lack insight, however they can be complex to arrange and are hindered by perceptions of coercion.³¹ A centralized resource that manages this process would prove beneficial.

BREAKDOWNS EXIST DURING THE TRANSFER OF CARE THAT IMPACT PATIENT OUTCOMES

The panel emphasized the frequency in which patients are “lost in the cracks” during transitions of care due to a fragmented health system, whether from inpatient to outpatient care, pediatric to adult care, specialty to general practice, or moving from one province to another.^{14,32}

Transitions are important events that can introduce the risk of breakdowns in a person’s care, increase the risk of relapse, and result in loss or miscommunication of crucial information.¹⁴

Additional support is necessary to navigate through the system, particularly connecting patients to care once they leave their existing frameworks. The previously mentioned national patient-support program could help to bridge this gap.

IMPROVING CARE FOR DIFFICULT-TO-REACH CLIENTS

Every region in Canada experiences significant challenges serving rural

and Indigenous communities.^{32,33} Further, there are no existing schizophrenia or early intervention programs available to people living in the Territories.³⁴ People often need to travel long distances to find care, and these populations frequently experience higher rates of mental illness.^{32,33,35} While telehealth and visiting programs have helped to provide care for these populations, involving other care providers, such as primary care and pharmacists, can help to share the burden of care and reduce the stigma.^{15,32}

CONCLUSION

The diverse perspectives shared during the discussion proved immensely valuable, highlighting the strength and passion that panellists bring to addressing the challenges of psychosis care. While the unmet needs of people with schizophrenia remain significant, even small improvements in care can profoundly enhance their quality of life. These insights emphasize the importance of fostering collaboration and adopting a unified approach, with a national framework for SSD management offering the potential for more consistent and effective support. ●

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