

Persons with Lived Experience A National Survey

In the summer of 2021, the Schizophrenia Society of Canada undertook two national online surveys, supported by AbbVie. One survey was for people with lived experience of early psychosis or schizophrenia, and one was for family members of people with lived experience of early psychosis or schizophrenia. 239 full completed surveys were from persons with lived experience (PWLE).

Intent of the Survey

- ◆ to understand the impact that positive symptoms, negative symptoms, and cognitive symptoms have on quality of life.
- ◆ to consider the side effects of anti-psychotic medications that most impact quality of life, and
- ◆ to better understand what helps and what hinders personal recovery journeys

Symptoms

PWLE respondents reported experiencing one or more symptoms over the year prior to the survey with



76%

reporting one or more **positive symptom**



94%

reported one or more **negative symptom**



97%

reported one or more **cognitive symptom**



delusions (39%) and disorganized speech and thoughts (37%) were the most reported positive symptom that impacted respondents lives



social withdrawal (39%), reduced motivation (38%) and reduced verbal communications (34%) were experienced by slightly more respondents than other negative symptoms



difficulty with attention and memory of information (60%) were the most reported cognitive symptoms that impacted respondents lives



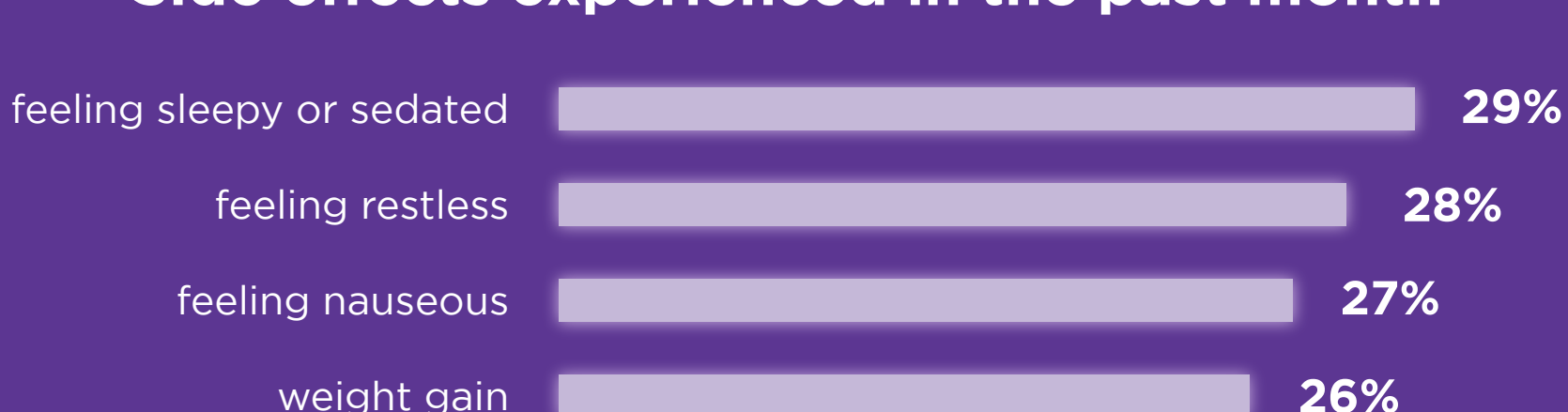
All categories of symptoms were reported to have moderately to greatly affected the quality of life of PWLE over the year prior to the survey.

Medication side effects

94%

of respondents were taking medications for early psychosis or schizophrenia at the time of the survey.

Side effects experienced in the past month



Respondents reported experiencing

Hypertension (31%)



Diabetes (26%), or



Cardiovascular problems (29%)

since starting their anti-psychotic medications.

The degree to which side effects were reported to affect quality of life in the past year were all rated between moderately and greatly.

Recovery

percentages of PWLE who considered where they were at in their recovery journeys



Aspects most helpful to them in their personal recovery journeys included having the **support of family, good sleeping habits, and spending time with the people that they love.**



What it all means

- ◆ Quality of life continues to be significantly impacted for people with early psychosis and schizophrenia.
- ◆ Managing symptoms and the side effects of medication is an ongoing process.
- ◆ Despite side effects and symptoms most respondents reported that they were progressing in recovery or were in full recovery.
- ◆ Further research and investment into evidence-based interventions that support recovery and further study and development of antipsychotics that have fewer side effects for the individuals using them are needed.