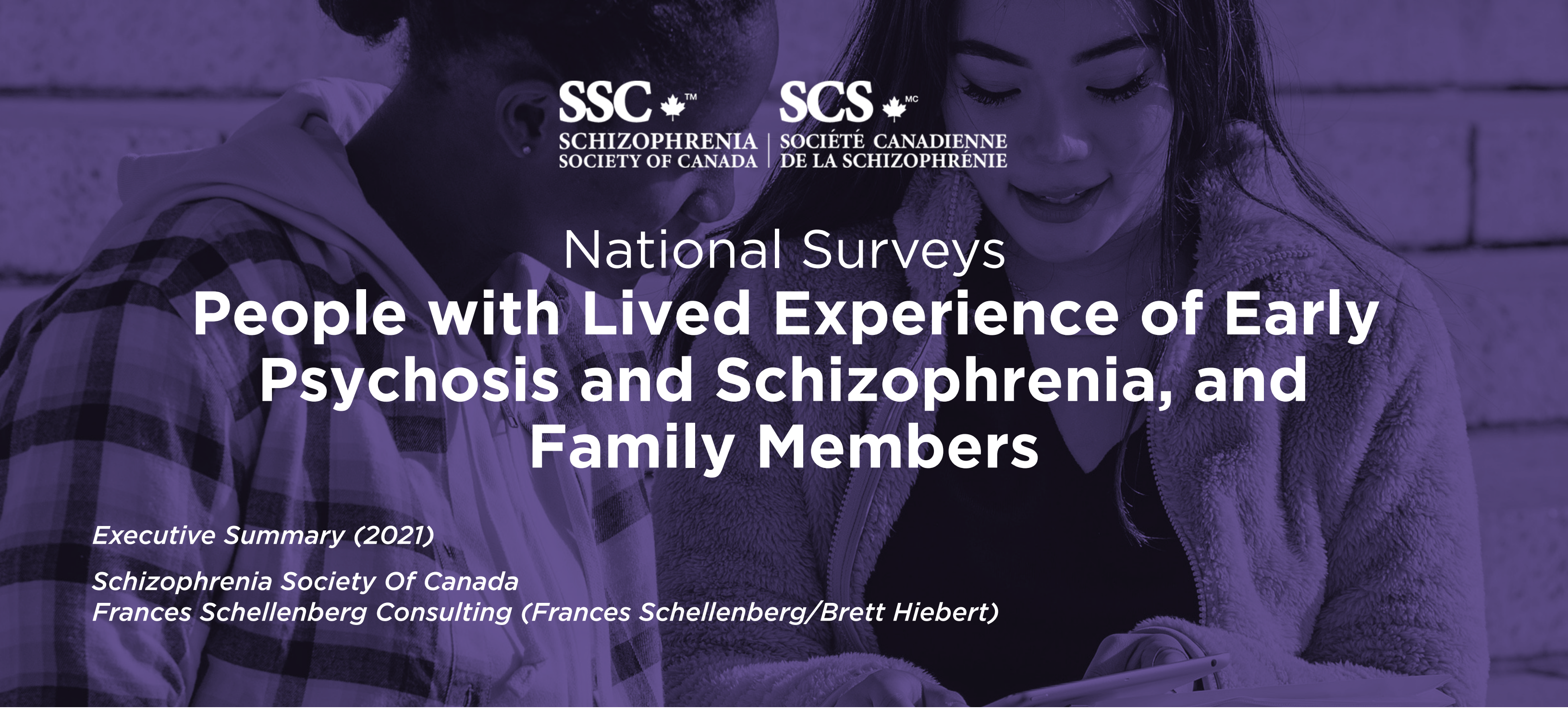

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National Surveys

People with Lived Experience of Early Psychosis and Schizophrenia, and Family Members

Executive Summary (2021)

Schizophrenia Society Of Canada
Frances Schellenberg Consulting (Frances Schellenberg/Brett Hiebert)

EXECUTIVE SUMMARY

In the early summer of 2021, the Schizophrenia Society of Canada undertook two national online surveys supported by AbbVie/Allergan, one for persons with lived experience (PWLE) of early psychosis or schizophrenia, and one for family members (FM) of people with early psychosis and schizophrenia. The intent of the surveys was to:

- gain a current understanding of the impact that positive symptoms, negative symptoms, and cognitive symptoms have on the lives of individuals with early psychosis and schizophrenia, from both the lived experience perspective and the family perspective.
- consider the side effects of anti-psychotic medications that most impacted individuals' quality of life, and
- better understand the journey of personal recovery that people with early psychosis and schizophrenia, and family members, take and what helps or hinders that journey.

In total, 239 full completed surveys from PWLE and 121 full completed surveys from FM were included in the final analysis. Sixty-eight percent of the PWLE respondents were male and almost half were 25 to 34 years of age. Seventy-seven percent were living with family at the time of the survey. For the FM survey, 65% of respondents were female with age being fairly equally distributed across age ranges. Forty-three percent had a family member with early psychosis or schizophrenia living with them.

PERSONS WITH LIVED EXPERIENCE (PWLE) SURVEY: SUMMARY RESULTS

Across all three categories of symptoms (positive, negative, and cognitive), a high percentage of 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

The positive symptom experienced by the highest number of respondents over the past year (39%) and in the past week that most impacted quality of life (18%) was ***delusions***. ***Social withdrawal (39%)*** and ***reduced motivation or apathy (38%)*** were experienced by slightly more respondents than other negative symptoms. The cognitive symptom experienced over the past year ***(60%)*** and over the past week that impacted quality of life ***(45%)*** by the highest number by respondents was ***difficulty with attention and memory of information***. Positive, negative, and cognitive symptoms were reported to have all moderately to greatly affected the quality of life of the PWLE respondents in the year prior to the survey.

A large majority of PWLE (94%) were taking medications for early psychosis or schizophrenia at the time of the survey. The side effects most experienced in the month prior to the survey by PWLE respondents included:

- ***feeling sleepy or sedated (29%),***
- ***feeling restless (28%),***
- ***feeling nauseous (27%), and***
- ***weight gain (26%)***

A somewhat high percentage of 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 year prior to the survey were all rated between moderately and greatly.

Despite the side effects and the symptoms experienced by respondents and the reported impact of these on quality of life, most considered themselves as either ***progressing in their recovery (62%)*** or ***in full recovery (31%)***, with ***7%*** reporting that they are ***struggling in their recovery***. Of the 17 aspects of recovery that were asked about, all were rated as very important to respondents, with having medications that have few side effects as the top-rated aspect. Having the support of family, good sleeping habits, and spending time with the people that they love were the aspects that most helped them in their personal recovery journeys.

FAMILY MEMBERS (FM) SURVEY: SUMMARY RESULTS

FM reported that their family member with early psychosis or schizophrenia experienced various cognitive symptoms over the past year (45-48%) to a high degree. Various positive symptoms (42-45%) and various negative symptoms (36-57%) were also reported at relatively high degrees in the year prior to the survey.

The positive symptom FM reported in their family member most in the year prior to the survey were ***hallucinations (45%)*** and ***disorganized behavior (45%)***. ***Reduced motivation or apathy (57%)*** and social ***withdrawal (49%)*** were reported as the most common negative symptom experienced over the past year. There was no specific cognitive symptom that was reported significantly more than the others, however difficulty with memory in general or understanding things occurred the most frequently in the year prior to the survey at 48%. Positive, negative, and cognitive symptoms observed by FMs were reported to have moderately to greatly affected the quality of life of the their family members in the year prior to the survey.

A large majority of FM (83%) reported that their family member was taking medications for early psychosis or schizophrenia. Feeling sleepy or sedated was the side effect most reported in the month prior to the survey by FM respondents at 39%, with feeling restless and weight gain as the next most reported. The degree to which side effects were reported to affect quality of life in the past year were rated between just less than moderately and greatly, with sexual problems having the highest rated impact on quality of life. FM respondents reported their family member experienced ***Hypertension (15%)***, ***Diabetes (13%)***, or ***Cardiovascular problems (12%)*** since starting their anti-psychotic medications.

74% of FM considered their family member as either ***progressing in their recovery (43%)*** or ***in full recovery (31%)***, with ***26%*** reporting that their family member was ***struggling in their recovery***. Of the 17 aspects of recovery that were asked about, all were rated as very important to extremely important to respondents, with having a safe and stable place to live as the top-rated aspect. FM respondents indicated that having the support of family, doing activities that they enjoy, and reaching out for help when they need it were also important aspects to their family member's personal recovery journeys.

CONCLUDING REMARKS

Although there are research studies that have considered the above issues, these national surveys have confirmed previous findings and have done so within a current, Canadian context. Future work could attempt to add more qualitative understandings of the results of these two surveys, bringing a more personal description to complement the survey results. Additionally, recruiting persons for discussion who would not have had access to the surveys online would serve to bring an ability to better generalize (or alternatively specialize) the picture of people's experience with early psychosis or schizophrenia. It may also be interesting to corroborate the findings of these surveys with service providers who work with people with early psychosis or schizophrenia.

There continue to be many unmet needs related to broadly accessing therapies and supports that have been shown through evidence to have positive impacts on negative and cognitive symptoms of early psychosis and schizophrenia. Further research and further investment into evidence-based interventions that support recovery are much needed. So too is investment needed to study and develop antipsychotics that have fewer side effects for the individuals using them.

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. While we know much about early psychosis and schizophrenia and the effects of symptoms, medications, and recovery, it is imperative to continue to hear from people with lived experience and family members on these issues. It is only through listening to and understanding individuals' personal experiences that we will authentically be able to continue to work toward improved treatments and services that will support recovery and a better quality of life for individuals with early psychosis or schizophrenia and their families.