

Care Partner Burden and Experiences with Schizophrenia: A National Canadian Survey

PCR38

G Babe¹, A Wong², SJ Seung², R Milan¹, S Tiggelaar¹, N Ship¹, J Wang³, C Summerville⁴, D Robinson⁵, H McNeely⁶, R Zipursky⁷, O Agid⁷

1. Boehringer Ingelheim, Burlington, ON, Canada; 2. HOPE Research Centre, Sunnybrook Health Sciences Centre, Toronto, ON, Canada; 3. Boehringer Ingelheim Corporation, Ridgefield, Connecticut, CT, USA; 4. Schizophrenia Society of Canada, Steinbach, MB, Canada; 5. Canadian Mental Health Association, London, ON, Canada; 6. McMaster University and St. Joseph's Healthcare Hamilton, Hamilton, ON, Canada; 7. Centre for Addiction and Mental Health, Toronto, ON, Canada

Introduction



- Schizophrenia is a chronic psychiatric disorder affecting 0.4% to 1% of the Canadian population and imposes nearly \$10 billion in costs^{1,2}
- Cognitive impairment associated with schizophrenia (CIAS) is a core feature of schizophrenia and is associated with poor outcomes, including inability to live independently, reduced quality of life (QoL), and higher healthcare use^{3,4}
- Family members and other informal care partners often bear a substantial caregiving burden in supporting individuals with schizophrenia, facing long-term emotional, financial, and occupational challenges^{5,6}
- Despite this burden, Canadian-specific data on the impact of CIAS and caregiving remain limited.

Methods



- A cross-sectional study using electronic surveys was conducted in Canada from October to December 2024. Surveys were distributed across Canadian patient organizations, clinics specializing in psychotic disorders, and market research panels, and recruited participants through convenience sampling. Participants were compensated for completing the survey.
- The survey included: 1) questions about demographics, caregiving information, and severity of CIAS experienced by the person in their care; and 2) validated instruments such as the Study Partner Global Impression of Severity (SPGI-S), EQ-5D-5L, and the Work Productivity and Activity Impairment Questionnaire (WPAI).
- Surveys were designed to be completed in 20-30 minutes, and were available in English and French.
- Care partners were eligible for the survey if they:
 - Were 18 years of age or older
 - Resided in Canada
 - Could read English/French
 - Self-identified as a care partner for a person with a formal diagnosis of schizophrenia
 - Were not a paid caregiver
- Descriptive statistics and group comparisons (Chi-Square, t-tests, ANOVA) were conducted using SAS v9.4, results were analyzed by CIAS severity.

Objectives

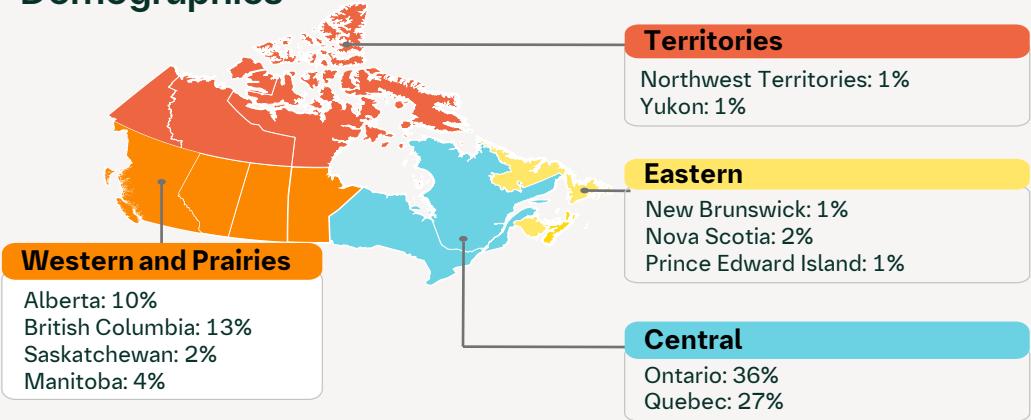


- This study aimed to describe the characteristics, caregiving experiences, and burden faced by care partners of people living with schizophrenia in Canada through an online survey.

Results

- 200 care partners completed the survey.

Demographics



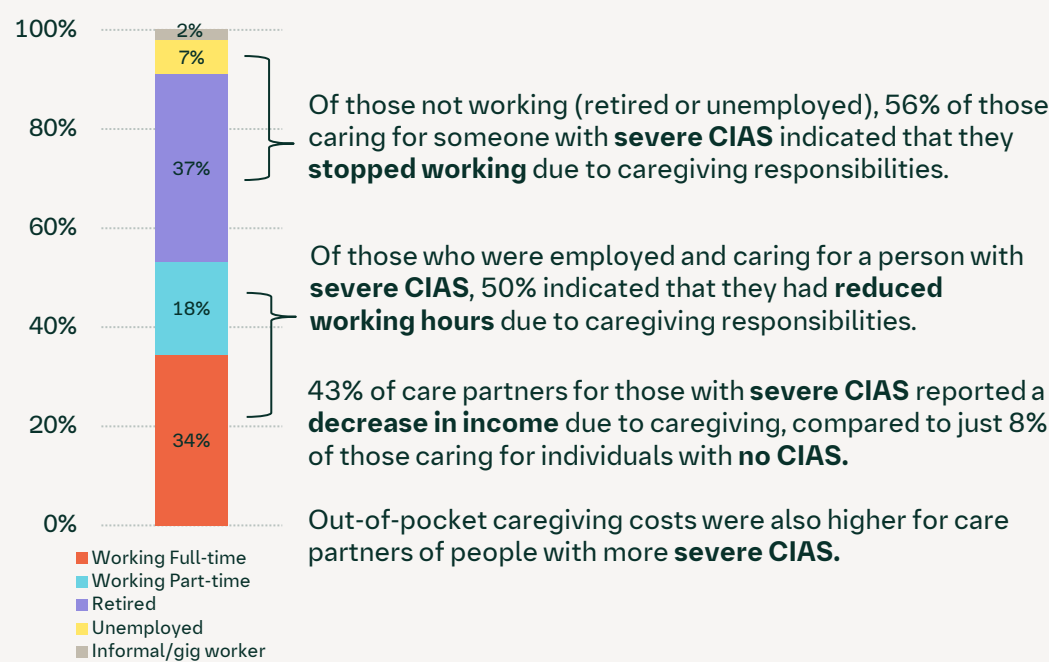
69%
Identified as women

54 years
Was the mean age (SD = 16)

72%
Had completed a college diploma/university degree

14 years
Of caregiving (SD = 10)

Employment, Income and Financial Impact

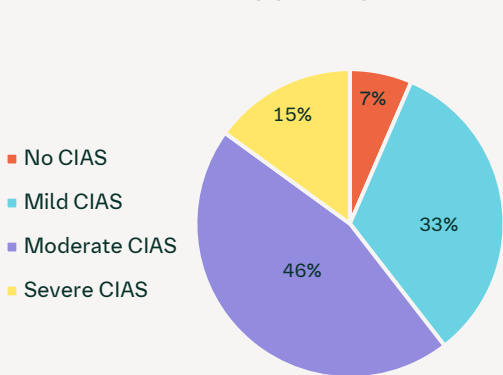


Medications, CIAS Severity, and Caregiving



According to care partners:

Study Partner Global Impression of Severity (SPGI-S)



- Most people living with schizophrenia use medications. These include: oral medications (56%), injectable medications (38%), and clozapine (35%)
 - There were mixed opinions on the perceived effects of medications on cognitive symptoms (44% improved, 30% worsened, 23% no effect).
- Hospitalizations **increased** with CIAS severity – 30% of care partners for a person with **severe CIAS** reported a hospitalization in the last 3 months, compared to none for those with no CIAS.
- Care partners of those with **severe CIAS** provided significantly more hours of direct care compared to those with no CIAS (32 ± 42 hours VS 5 ± 8 hours).

Work Productivity and Quality of Life (WPAI and EQ-5D-5L)

WPAI Subscale	No CIAS	Mild CIAS	Moderate CIAS	Severe CIAS
Absenteeism (% work time missed)	0%	6%	9%	6%
Presenteeism (% impairment while working)	20%	24%	42%	37%
Overall Work Impairment	20%	28%	46%	38%
Activity Impairment	18%	25%	35%	52%

WPAI scores were significantly affected by CIAS severity. Those caring for people with **moderate or severe CIAS** showed higher levels of work and activity impairment.

Mean (SD) EQ-5D-5L scores were 0.8 (0.2) for all care partners, with higher anxiety/depression and pain subscores among care partners of people with **severe CIAS**.



Care partners highlighted the **emotional toll** of caregiving (69%), **need for personalized care** (63%), and **societal support** (45%); 73% hoped for care recipients' independence and better daily functioning.

Conclusions

- Caring for individuals with schizophrenia places a substantial emotional, financial, and time burden on care partners.
- Caring for someone with more severe CIAS is associated with greater burden – greater CIAS was linked to higher caregiving hours, lost income, reduced employment, and worse quality of life for care partners.
- Work productivity was substantially affected, with significant presenteeism, absenteeism, and overall productivity loss among employed care partners.
- Care partners' quality of life declined with CIAS severity, particularly anxiety, depression and pain.
- Findings highlight the urgent need for tailored support strategies to reduce care partner burden and improve well-being.

Abbreviations

ANOVA, analysis of variance; CIAS, cognitive impairment associated with schizophrenia; EQ-5D-5L, EuroQoL five-dimensional, five-level questionnaire; HCRU, healthcare resource utilization; QoL, quality of life; SAS, Statistical Analysis System; SD, standard deviation; SPGI-S, Study Partner Global Impression of Severity; SOLS, Schizophrenia Quality of Life Scale; WPAI, Work Productivity and Activity Impairment Questionnaire.

References

- Canadian Chronic Disease Surveillance System (CCDSS) data. Available from: <https://health-infobase.canada.ca/ccdss/data-tool/Comp?G=35&V=5&M=1>
- Lecomte T, et al. Can J Psychiatry. 2022;67(3):172-175.
- Kadikia A, et al. Schizophr Res Cogn. 2021;28:100233.
- McCutcheon RA, et al. Mol Psychiatry. 2023;28(5):1902-1918.
- Hsiao C-Y, Lu H-L, Tsai Y-F. Caregiver burden and health-related quality of life among primary family caregivers of individuals with schizophrenia: a cross-sectional study. Qual Life Res. 2020;29(10):2745-2757.
- Awad AG, Voruganti LN. The burden of schizophrenia on caregivers. Pharmacoeconomics. 2008;26(2):149-162.

Disclosures

This study was supported and funded by Boehringer Ingelheim. The authors met the criteria for authorship as recommended by the International Committee of Medical Journal Editors (ICMJE) and were fully responsible for all content and editorial decisions, were involved at all stages of poster development, and have approved the final version. The authors did not receive payment related to the development of the poster.

Acknowledgements

The authors would like to acknowledge the following: Schizophrenia Society of Canada, British Columbia Schizophrenia Society, Mental Health Recovery Partners, Schizophrenia Society of Alberta, Schizophrenia Society of Alberta Support Group, Schizophrenia Society of Saskatchewan, CMHA Winnipeg, CMHA Thunder Bay, CMHA London, Mood Disorders Society of Canada, Schizophrenia Society of Saskatchewan Family Support Group, Institute for Advancements for Mental Health, IAM Support Group, Société québécoise de la schizophrénie, Schizophrenia Society of New Brunswick, Hope for Mental Health, Schizophrenia Society of Newfoundland/Labrador, The Royal at Ottawa, CAP santé mentale, Thunder Bay Regional Health Sciences, Centre for Addiction & Mental Health, CAMH, Sunnybrook Health Sciences Centre, William Osler Health System, St. Joseph's Healthcare Hamilton, Western University Research – Parkwood, REACH BC, and Ami Quebec.



Boehringer
Ingelheim

SSC
SCHIZOPHRENIA
SOCIETY OF CANADA