

## **The Economic Burden of Schizophrenia and Adequacy of Existing Medications Survey in Ontario**

### **Overview:**

Approximately 1% of the population has schizophrenia. In Ontario, that's about 14,100 people. For these people, their families and their caregivers, the benefits of medications and programs that help manage schizophrenia symptoms and improve their quality of life are clear. For the rest of Ontarians, however, these benefits may not be as obvious.

The fact is the economic burden of schizophrenia affects all Ontario residents. In a 2004 study, Goeree and associates determined that the direct and indirect costs of schizophrenia in Canada totaled \$6.85 billion annually, which at the time represented approximately 1.7% of national healthcare expenditures.<sup>1</sup> Extrapolating from these figures, Ontario's share of this cost is approximately \$2.6 billion per year.

Providing the people who live with schizophrenia with access to the best available treatments—treatments that can alleviate some of the factors that contribute to the economic burden of schizophrenia is, therefore, a goal that all Ontarians should strive for.

### **The Economic Burden of Schizophrenia:**

Goeree and associates' study, "The Economic Burden of Schizophrenia in Canada in 2004," outlines a variety of factors that make up the \$6.85 billion cost of schizophrenia in Canada. These include:

- Direct healthcare and non-healthcare costs of \$2.02 billion annually, such as the cost of hospitalization, visits to psychiatrists, and the cost of prescription medications;
- 670,245 acute hospital days per year for people with schizophrenia and an additional 1,696,478 days for non-acute hospitalization;
- A high unemployment rate for people with schizophrenia which results in a loss of productivity. According to the Schizophrenia Society of Ontario, fewer than 20% of people with schizophrenia are employed;<sup>2</sup>
- 631,192 federal or provincial income assistance plan payments made per year to people living with schizophrenia;
- A lifetime risk of suicide for people who have schizophrenia that is 15-25 times higher than for the general population;
- 356,002 incarceration days per year for inmates with schizophrenia in federal or provincial jails and prisons.

Given that the population of Ontario represents approximately 38% of the total population of Canada, and using Goeree's estimates of the cost of schizophrenia in Canada, the economic cost of schizophrenia in Ontario is approximately \$2.6 billion annually.

### **The Cost of Weight Gain:**

Another factor that adds to the economic burden of schizophrenia, which is not included in studies such as Goeree's, is overweight and obesity. The World Health Organization has called the spread of overweight and obesity "one of the

greatest neglected public health issues of our time.”<sup>3</sup>

People who take medications for schizophrenia are overweight or obese at a rate greater than that of the general population. In a US study published in 2004, Catapano and Castle<sup>4</sup> indicate that an estimated 40-60% of people with schizophrenia are obese or overweight, while Kolotkin<sup>5</sup> and associates found that 63% of the participants with schizophrenia in their study were obese. Several studies have indicated that the factors that contribute to overweight and obesity among people with schizophrenia include illness-related factors and the use of antipsychotic medications.<sup>6</sup>

An additional concern is that it may be more difficult to treat obesity in people who have gained weight largely due to the use of psychotropic medications. Centorrino and colleagues indicate that “It is extremely difficult for chronically and severely mentally ill patients who require antipsychotic treatment to eat less and exercise more when their treatment increases appetite and produces fatigue and sedation, and their illnesses decrease motivation and limit social interactions and activities.”<sup>7</sup>

In a study on the cost of obesity in Ontario published in 2001, Colman and associates examined the cost to society of overweight and obesity, which they defined as having a body mass index (BMI) higher than 27.0. In determining this cost, the researchers focused primarily on the expense of treating obesity-related illnesses. They found that the cost of obesity in Ontario for 10 illnesses, for which comorbidities for obesity have been well established, totaled \$656.6 million per year. Because this number is based only on 10 illnesses, the authors believe it is a conservative estimate. When additional factors are taken into account, “it is reasonable to conclude that unhealthy weights could cost the Ontario health care system more than \$1.1 billion per year” in direct costs alone.<sup>8</sup>

Given that approximately 1% of the population lives with schizophrenia, a conservative estimate of the cost to society of obesity among people with schizophrenia is in the area of \$11 million annually—a conservative figure due to the fact that obesity rates among people with schizophrenia are higher than for the general population. An additional concern is that a survey of patient satisfaction with antipsychotic medication found that of those who experienced weight gain as a side effect, 73% reported it to be “quite or extremely distressing,”<sup>9</sup> which raises the possibility that weight gain may affect a patient’s decision to stop taking medication.

### **Relapse and Compliance:**

The decision to stop taking medication introduces another factor affecting the economic burden of schizophrenia: hospitalization costs for patients who suffer relapses, which are often the result of discontinuing medication or not taking the recommended dosage. One of the conclusions of the Goeree and associates’ study is “prevention of schizophrenia relapse resulting in hospitalization may be critical to effective patient management and cost containment.”<sup>10</sup>

Other studies have detailed the frequency of relapse among people who have schizophrenia, and the fact that the predominant rationale for readmission to hospital is not following recommended clinical treatment. Statistics on relapse indicate that 30-50% of patients with schizophrenia, other psychotic disorders, or major mood disorders are readmitted to hospital within one year of discharge, while 25% of people with chronic schizophrenia will be readmitted within three months.<sup>11</sup>

In a year 2000 survey of 2,663 people taking schizophrenia medication in the United Kingdom, 44% of respondents reported that they had stopped taking their medication without the support of their doctors.<sup>12</sup> This number is supported by several other studies, indicating that the incidence of not following recommended treatment among patients managing schizophrenia ranges from 33-60%.<sup>13</sup>

In the United States, researchers have found that total annual direct costs associated with schizophrenia range from \$19-\$33 billion (US), while the costs for readmission to hospital exceed \$2.3 billion.<sup>14</sup> Extrapolating the cost of relapse as a percentage of total direct costs associated with schizophrenia in the US results in a range from 7-12%, which when applied to Ontario places the estimated annual cost of relapse at \$182-\$312 million.

## **The Adequacy of Existing Medications Survey in Ontario:**

The issues of relapse and compliance and patient distress over weight gain point to the importance of patient satisfaction with existing antipsychotic medications. Studies have shown that patient satisfaction is associated with compliance with recommended treatment.<sup>15</sup> How patients feel about existing medications is, therefore, essential to a discussion of the economic burden of schizophrenia.

In their survey of people who take medication for the treatment of schizophrenia, the National Schizophrenia Fellowship in the United Kingdom found that “side effects of medicines used in the treatment of mental illness are widely experienced and mostly not tolerable.”<sup>16</sup> Of those who experience particular side effects, the following percentages rated their severity as “bad” or “very bad”:

- 62% - feelings of inner restlessness
- 62% - weight gain
- 64% - loss of energy

Another study of patients diagnosed with schizophrenia conducted by Gray and associates found that 64% of respondents said they were experiencing side effects, and of these, 34% said the side effects they were experiencing were not tolerable.<sup>17</sup>

In 2009, Magpie Publishing, Inc. conducted an online survey of schizophrenia patients and caregivers titled “Patient Satisfaction with Medication in Ontario.” The survey was promoted on the internet and to all *SZ Magazine* and *Anchor: Conquering Depression* magazine subscribers. The results of the survey of Ontario residents are included in this report.

Nearly all respondents (96.6%) are taking antipsychotic medications for their schizophrenia. Forty-two percent of respondents indicated that they had stopped taking antipsychotic medication without the advice of their doctor, a finding consistent with the results of other international surveys. Of the Ontario respondents who stopped taking their medication, 50% indicated side effects as the reason for discontinuing their medication, with 25% of respondents citing weight gain as a specific side effect that influenced their decision. Overall, 87.7% of respondents experienced weight gain. It was also the number one side effect indicated as a reason for respondents’ dissatisfaction with their current medication. Twenty-two percent of respondents are either “dissatisfied” or “very dissatisfied” with their current medications. Clearly, there is a treatment gap.

Consistent with the findings of the National Schizophrenia Fellowship survey in the United Kingdom, Magpie Publishing’s survey of Ontario residents found that high numbers of people taking antipsychotic medications stated that side effects are difficult to tolerate. Of Ontario residents experiencing particular side effects, the following percentages rated their severity as “bad” or “very bad”:

- 53.3% - feelings of inner restlessness
- 70.9% - weight gain
- 65.3% - loss of energy

Other side effects rated as “bad” or “very bad” include loss of energy (65.3%) and sexual side effects (52.8%).

Among the Ontario respondents, 40.3% had visited an emergency room within the last six months, with 15.1% indicating that they had done so more than once, and 31.5% indicating they had been hospitalized during the same period (11.1% having been hospitalized more than once in the last six months).

The percentage of respondents who indicated interest in finding a new medication is 42.8%. Side effects were cited as the number one reason for patient dissatisfaction with their current medication as well as the number one reason why they stopped taking medication without the advice of their doctors. Nearly all (92.6%) answered “yes” when asked, “By not including Zeldox on the provincial formulary, do you think the Ontario government is discriminating against Ontario patients with schizophrenia and their families?”

## **Conclusions:**

Given the economic burden of healthcare, residential care, the administration of income assistance plans, incarceration, obesity and relapse, and productivity losses associated with schizophrenia, the availability of effective treatment for the management of schizophrenia should be of concern to all Ontario residents.

As Goeree and associates point out, the cost of prescription medications (which can influence some of the factors contributing to the economic burden of schizophrenia) represents only 7% of total health and non-healthcare costs related to schizophrenia in Canada.<sup>18</sup> Issues of relapse and non-compliance with recommended treatment have a demonstrated association with the lack of patient satisfaction with current medication and treatment programs, and represent a significant annual cost to society, as does the loss of productivity associated with unemployment and premature death. Offering people who have schizophrenia access to medications that increase patient satisfaction and minimize intolerable side effects represents only a small fraction of the total cost of schizophrenia, and has the potential to reduce its economic burden.

As Goeree's study concludes, "Programs targeted at improving patient symptoms and functioning to increase workforce participation have the potential to make a significant contribution in reducing the cost of severe mental illness in Canada."

The recent "Patient Satisfaction with Medication in Ontario" survey suggests that a significant treatment gap exists among schizophrenia patients in Ontario because of either unsatisfactory effectiveness or tolerability (22.4% are either "dissatisfied" or "very dissatisfied" with current medications). Nine out of 10 experienced weight gain and 40% had visited an emergency room in the past six months. Nearly half (42.8%) are interested in a new medication.

The Honourable David Caplan, Minister of Health and Long-term Care, has correctly made mental health a top priority of the Ontario government. His newly released discussion paper titled "Every Door is the Right Door—Towards a 10-year Mental Health and Addictions Strategy" concluded that "investing in actively supporting people to stay mentally healthy saves money. Every \$1 spent on mental health and addictions saves \$7 in health costs and \$30 in lost productivity and social costs." Therefore, the Minister needs to go one step further and mandate the Ontario Drug Benefit program to align its medication reimbursement policies with the Mental Health Strategy by making new treatment options such as Zeldox available to Ontarians who suffer from mental illness. Doing so would both reduce healthcare spending and avoid discriminating against people living with mental illness.

## **Study Limitations:**

As a study based primarily on a review of existing literature, some findings rely on extrapolation in order to estimate the costs associated with schizophrenia in Ontario specifically.

The sample size of Ontario residents to the Patient Satisfaction with Medications survey may be too small to make the results definitive, however, they are consistent with the responses of previous larger-scale surveys, such as the one conducted by the National Schizophrenia Fellowship.

## References

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18. See note 1 above.

## Survey Results: Patient Satisfaction with Medication in Ontario

Number of Responses: 58 (total responses)

<b>Are you currently taking antipsychotic medication for schizophrenia and/or have you done so in the past?</b>		
<b>Responses</b>	<b>58</b>	
Yes	56	96.6%
No	2	3.4%

<b>What medication(s) you are currently taking?</b>		
<b>Responses</b>	<b>75</b>	
Risperdal	24	32.0%
Zyprexa	11	14.7%
Clozapine	16	21.3%
Depot (Injection)	6	8.0%
Seroquel	8	10.7%
Haldol	5	6.7%
Invega	3	4.0%
Geodon	2	2.7%

**What medication(s) you are currently taking? (Other):  
Responses:**

Effexor -pariet -zocor
Abilify
Cymbalta, nitoman
Wellbutrin xl
Effexor
Celexa, and clonidine
Celexa, tegretol, clonazepam
Lithium
Cylexa, prevacid,
Lithium, celexa
Metformin
Anti depressants
Epival, prozac, artane, clonazepam,
Effexor
Prescription sleep aid
Colanzapam
Risperdone la im
Ativan, wellbutrin, cipralex

<b>How satisfied are you with your current medication?</b>		
<b>Responses</b>	<b>58</b>	
Very Satisfied	11	<b>19.0%</b>
Satisfied	27	<b>46.6%</b>
Not Sure	7	<b>12.1%</b>
Dissatisfied	5	<b>8.6%</b>
Very Dissatisfied	8	<b>13.8%</b>

**If you are not satisfied with your current medication, please indicate why.**

**Responses:**

I don't need it.
Massive weight gain
Potential for long-term side effects such as tardive dyskinesia
Side effects and costly
I feel weak and i drool
Have not to pre catastrophic condition
Losing weight
Still exhibiting psychotic symptoms
Large weight gains
Medications indirectly cause one to gain weight...Due to an increased appetite....Also losing hair and i wish that prozac would be a weight reducing medication again! Furthermore, i think these negative side effects are a form of stigmatization.
I still feel my paranoia
Side effects
Weightgain, tired
Side affects
Still many episodes
Not effective enough in decreasing symptoms
Weight gain

<b>Did your doctor switch you to a different medication in the last 6 months?</b>		
<b>Responses</b>	<b>56</b>	
Yes	18	<b>32.1%</b>
No	38	<b>67.9%</b>

<b>Have you ever stopped taking medication without the advice of your doctor?</b>		
<b>Responses</b>	<b>57</b>	
Yes	24	<b>42.1%</b>
No	33	<b>57.9%</b>

**If you have stopped taking medication without the advice of your doctor, please indicate why.**

**Responses:**

I was overmedicated
Weight gain, sexual side effects
Gaining weight
This patient does not believe she is ill
Thought i could live without it

Before when i was taking risperdal, i gained a lot of weight, and i thought i no longer needed the medication. But now that i am taking invega, i've lost about 25 pounds since starting the new med. I just wish that it would be covered because it is so expensive. I'm on 12 mg/day and it cost close to \$400 a month.

Not sz im ok

Thought that could function without medication

Cost

I didn't realise that my symptoms of schizophrenia would return. It was at the time i was first diagnosed and i didn't realize how much i needed the medication.

Weight gain and libido

Apathy, weight gain

Side effects

Paranoia

Side-effects

Too tired

To lose weight

Poorly functioning, tired

Didn't think he needed it

No sz

Very ill, denial, doing illicit drugs at the time

Relapse

Side fx of haldol

Didn't think i needed anymore

**Please indicate the side-effects you have experienced with your current medication as well as the severity of these side-effects.**

**Responses:**

Blindness

Dizziness/fatigue/depression/anxiety/apathy

Unwanted weight gain, blurred vision, constipation and dehydration

Can't handle being out in the sun, my eyes react.

Sleepiness,dizziness

Stiff joints

Paxil

Stuff related mostly to the weight gain (high blood pressure, cholesterol)

Blindness

Weakness and drool

Suicide attempts

Cognitive

Drooling

Insomnia, headaches - tolerable with sleep aid and tylenol

**Muscle spasms: Experienced?**

**Responses**

**54**

Yes

25

**46.3%**

No

29

**53.7%**

<b>Muscle spasms: How severe was it?</b>		
<b>Responses</b>	<b>28</b>	
Tolerable	21	75.0%
Bad	4	14.3%
Very Bad	3	10.7%

<b>Muscle shaking/tremors: Experienced?</b>		
<b>Responses</b>	<b>53</b>	
Yes	23	43.4%
No	30	56.6%

<b>Muscle shaking/tremors: How severe was it?</b>		
<b>Responses</b>	<b>27</b>	
Tolerable	21	77.8%
Bad	5	18.5%
Very Bad	1	3.7%

<b>Feelings of inner restlessness: Experienced?</b>		
<b>Responses</b>	<b>54</b>	
Yes	43	79.6%
No	11	20.4%

<b>Feelings of inner restlessness: How severe was it?</b>		
<b>Responses</b>	<b>45</b>	
Tolerable	21	46.7%
Bad	20	44.4%
Very Bad	4	8.9%

<b>Weight gain: Experienced?</b>		
<b>Responses</b>	<b>57</b>	
Yes	50	87.7%
No	7	12.3%

<b>Weight gain: How severe was it?</b>		
<b>Responses</b>	<b>48</b>	
Tolerable	14	29.2%
Bad	15	31.3%
Very Bad	19	39.6%

<b>Loss of energy: Experienced?</b>		
<b>Responses</b>	<b>57</b>	
Yes	44	77.2%
No	13	22.8%

<b>Loss of energy: How severe was it?</b>		
<b>Responses</b>	<b>52</b>	
Tolerable	18	34.6%
Bad	15	28.8%
Very Bad	19	36.5%

**Sexual side-effects: Experienced?**

<b>Responses</b>	<b>53</b>	
Yes	28	52.8%
No	25	47.2%

**Sexual side-effects: How severe was it?**

<b>Responses</b>	<b>32</b>	
Tolerable	13	40.6%
Bad	10	31.3%
Very Bad	9	28.1%

**Effects on eyes: Experienced?**

<b>Responses</b>	<b>56</b>	
Yes	21	37.5%
No	35	62.5%

**Effects on eyes: How severe was it?**

<b>Responses</b>	<b>26</b>	
Tolerable	17	65.4%
Bad	5	19.2%
Very Bad	4	15.4%

Please indicate the side-effects you have experienced with your current medication as well as the severity of these side-effects (Other):

**Responses:**

- Cognitive
- Drooling
- Insomnia, headaches - tolerable with sleep aid and tylenol
- Suicide attempts
- Stiff joints
- Weakness and drool
- Blindness
- Stuff related mostly to the weight gain (high blood pressure, cholesterol)
- Sleepiness, dizziness
- Can't handle being out in the sun, my eyes react
- Dizziness/fatigue/depression/anxiety/apathy
- Unwanted weight gain, blurred vision, constipation and dehydration

**Has your illness affected your ability to find or keep a job?**

<b>Responses</b>	<b>58</b>	
Yes	43	74.1%
No	15	25.9%

**Are you interested in finding a new medication?**

<b>Responses</b>	<b>56</b>	
Yes	24	42.8%
No	32	57.2%

<b>Does your doctor discuss the different types of medications available with you?</b>		
<b>Responses</b>	<b>58</b>	
Yes	36	62.1%
No	22	37.9%

<b>Who is your primary doctor?</b>		
<b>Responses</b>	<b>58</b>	
Family Doctor	13	22.4%
Psychiatrist	35	77.6%

<b>Have you visited an emergency room in the last 6 months?</b>		
<b>Responses</b>	<b>53</b>	
Never	33	62.3%
Once	13	25.2%
Twice	3	5.7%
Three times or more	5	9.4%
Not Sure/Prefer not to Answer	1	1.9%

<b>Have you been hospitalized in the last 6 months?</b>		
<b>Responses</b>	<b>54</b>	
Never	36	66.7%
Once	11	20.4%
Twice	4	7.4%
Three times or more	2	3.7%
Not Sure/Prefer not to Answer	1	1.9%

<b>Are you filling in this survey for yourself?</b>		
<b>Responses</b>	<b>58</b>	
Yes	38	65.5%
No	30	34.5%

The Canadian Expert Drug Advisory Committee (CEDAC) recommends that provinces cover a new antipsychotic medication (Zeldox). Eight provinces provide it to patients as a treatment option (only Ontario and PEI do not). By not including Zeldox on the provincial formulary, do you think the Ontario government is discriminating against Ontario patients with schizophrenia and their families?

<b>Responses</b>	<b>54</b>	
Yes	50	92.6%
No	4	7.4%

#### Personal Information:

<b>Sex:</b>		
<b>Responses</b>	<b>58</b>	
Female	22	37.9%
Male	36	62.1%

<b>Age:</b>		
<b>Responses</b>	<b>58</b>	
18-24	5	8.6%
25-34	26	44.8%
35-49	16	27.6%
50-59	8	13.8%
70+	3	5.2%

<b>Province:</b>	
<b>Ontario</b>	<b>100%</b>
<b>Other Province or State:</b>	<b>Not Applicable</b>

<b>Employment Status:</b>		
<b>Responses</b>	<b>55</b>	
Employed	21	38.2%
Unemployed	34	61.8%

<b>Living Situation:</b>		
<b>Responses</b>	<b>58</b>	
Living Independently	25	43.1%
Living with a caregiver	33	56.9%