

Executive Summary

Respite Needs of People Living with Schizophrenia

Results of a National Survey of Schizophrenia Society of Canada Members



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SCHIZOPHRENIA SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCHIZOPHRÉNIE
UNE SOURCE D'ESPOIR, DE SOUTIEN ET D'ENTRAIDE.



Introduction:

"The sadness of the illness never goes away so the emotional strain is always there."

"A break offers mental, psychological relief but at the same time, it allows me to behave as though the problem doesn't exist anymore, and provides a moment of escape."

"Respite means being free of dealing directly with the perceptions and utterances of those who are in a mentally ill state. This is impossible to achieve if such a person is a member of your immediate family. The stress just builds and builds, calling on more reserves and patience than most ordinary people possess."

In 2005, the Schizophrenia Society of Canada surveyed its members to learn more about their needs for respite supports and services. This study was funded by the J.W. McConnell Family Foundation as part of a larger project to examine the respite needs of family caregivers in Canada. One important goal was to discover what respite meant to the families surveyed. A second goal was to survey people who were living with schizophrenia to find out what kinds of respite supports and services would be acceptable to them.

This report provides a brief executive summary of the findings. A more detailed report is available from the Schizophrenia Society of Canada (contact details are provided at the end of this report).

CAREGIVER SURVEY:

Three hundred and sixty-two caregivers were surveyed spanning every region of Canada. Provincial membership lists were used to draw random samples for each area. Surveys were mailed out with the regular Society Newsletter. Stamped, self-addressed envelopes were included to encourage a high return.

The typical responder was an aging mother who was providing care to an unmarried, unemployed, middle-aged son with schizophrenia who was actively involved in the mental health treatment system. In the year prior to the survey, a third of respondents had been providing care almost every day. In addition to emotional support, the most common types of care provided included financial support and assistance, help with instrumental activities (such as housekeeping), general supervision and time management, and social support. One in every two caregivers were actively involved in coordinating health and mental health care and one in every four provided personal care (such as bathing or help with medications). Almost half of the family members responding were providing care and assistance in multiple areas.

COPING WITH CAREGIVING:

Three quarters of the caregivers surveyed expressed some difficulties coping with their caregiving role. Social and practical support from family, friends and mental health providers was often lacking, and two-thirds rarely had enough time off from caregiving to pursue their own activities. One in ten often felt overwhelmed and stressed out.

Three quarters of responders reported that caregiving had negatively impacted one or more areas of their life, and one in five reported pervasive impacts across multiple areas of functioning. For example, two-thirds reported that caregiving had negatively impacted their emotional health, and almost half felt that it had been detrimental to their physical health. A quarter felt that their quality of life had steadily declined since they began caregiving while a third felt that their quality of life fluctuated. Most often, caregiving interfered with family members' ability to attend to their own health and wellness, but there were also negative impacts on social support, family routines, and family functioning—often making it difficult to maintain relationships with family and friends.

THE MEANING & IMPORTANCE OF RESPITE:

Caregivers told us, in their own words, what respite would mean to them. Overwhelmingly, they said rest and renewal without fear—a worry-free breather. For some, this meant a few hours a day when they could pursue their own interests, take a break from daily routines to recharge, and regroup. For others, it meant having a temporary replacement—someone who was knowledgeable about schizophrenia, caring, and who could be trusted to ensure that their loved ones were safe and happy. For still others, it meant a hiatus; a brief intermission; a block of time away to recharge and refresh.

In many instances respite meant providing adequate rehabilitation and community supports to ensure that care recipients had a place to go where they could be happy and involved in activities that were meaningful, interesting, and commensurate with their intelligence and skills. It also meant providing opportunities for companionship and socialization, to help loved ones create emotional ties that transcended the caregiver role—opportunities to decrease emotional dependencies and enhance social skills.

"Respite means having a break from my son. He lives with me at the moment in a one bedroom apartment, sleeps on the sofa or floor as the whim directs him. He seldom goes out, he has no friends, although I'm expecting he'll go out more in the warmer weather."

"Our life seems to be governed completely by the illness and a break away would be so helpful."

"Respite means time to take care of my physical and mental needs so that I can be a better caregiver. Time to recharge and reconnect with my husband."

"Respite means a break, a rest from what you are doing with the knowledge that the person you are caring for is well looked after, happy, safe."

"I am not a direct caregiver. We don't live in the same town. Most of my care is financial assistance. I am 69 and still working to make ends meet. I wonder if I will ever be able to retire."

"I feel hampered most of all by my financial position. My medication costs so much that I would be unable to pay for it if I were working. I would also like to be an owner of a computer. Life would be a lot easier if I did not have to worry about enough money for food. Friends and family try to help, but I feel their understanding of my illness is limited."

"The first challenge has been coping with my illness; the second is being able to find understanding friends; the third is facing a great deal of solitude. Since family members have to go out and earn a living, the person affected by illness is often alone with her thoughts, which only breeds anxiety."

The majority of family members felt that it was highly important to have breaks away from caregiving in order to rest and recharge and they described a wide range of emotional, social, instrumental, health, and quality of life benefits that would result. Despite this, the majority (three quarters) had never used a respite service. A third didn't know of any respite services available in their communities. Others felt that they were ineligible because their care recipient did not live in their home (even though they may still be providing considerable emotional and instrumental support), or were reluctant to seek support because they had gotten along without respite services so far. One in five indicated that their care recipient felt uncomfortable accessing outside respite services.

CARE RECIPIENT SURVEY:

In order to determine what types of supports and services would be acceptable to care recipients, we also surveyed 172 members of the Schizophrenia Society of Canada who were living with schizophrenia. The average responder was a single, unemployed, middle-aged male with schizophrenia. The majority reported that their overall level of mental health had stayed steady over the past year or improved. A small percentage (7%) thought their mental health was worse.

The majority reported that they were experiencing difficulty coping with their mental illness even though, for most, their support needs had not increased over the past year. Approximately one in five indicated that they needed more help now, than a year ago. Support in managing their illness came from a variety of sources. The two main ones—identified by three quarters—were family members and mental health providers, but family doctors and friends were also identified by about a third.

Respondents reported accessing a wide range of services and supports to help them manage their illness. Consumer groups were considered to be the most valued service by those who used them, but only 15% of responders had used a consumer group in the year prior to the survey. Similarly, most of those using overnight respite programs reported them to be of considerable value, however only 5 individuals (3% of the sample) used them. Programs that were considered to be of least value included legal services (used by only 3%), family therapy (used by 5%), and day care or day hospital programs (used by 5%). Individual therapy and medication management were the most frequently used services and reported to be of considerable value by those who used them.

The greatest deficiencies (reported by half) were with respect to support for education and training. Approximately one in four identified a need for more money for leisure activities, practical help around the house, and support to find a job. One in five reported that they rarely or never got enough information from mental health providers about treatment options or coping strategies, and approximately one in ten reported that they rarely or never received enough support from family, friends, or mental health providers.

Care recipients identified a wide range of services and supports that they believed would help them better manage their illness. Chief among these was the creation of better public attitudes toward people with a mental illness and the reduction of social stigma. Better access to traditional health and mental health services (such as family doctors or crisis services) were among the least frequently cited areas of need, being identified by only about one in ten responders.

PROGRAM IMPLICATIONS:

Findings from these surveys indicate that there is a great need for respite services that simultaneously meet the needs of family caregivers and people with schizophrenia. With that in mind, the following programs and supports should receive highest priority:

- companionship programs that address the social, emotional, and leisure needs of people who have schizophrenia while at the same time meeting the respite needs of their care-givers,
- flexible in-home supports for care-givers and care-recipients that are (a) provided by people who are knowledgeable about schizophrenia, (b) acceptable to care recipients, (c) acceptable to care providers, and (d) easily titrated to meet changing needs,
- partial and full day programs that provide a safe and stimulating environment for people with schizophrenia to further their education, training, and job preparedness,
- overnight beds that can be easily accessed by people with schizophrenia to provide respite from their usual care-giving environment and/or added supports in times of greater need.

“Respite means quality time for the caregiver and the client. A time out to renew the caregivers vitality and a time out for the client to learn new skills or hobbies or simply socialize.”

“It is difficult to live with schizophrenia because of the stigma attached.”

“It would be great if respite was recognized a necessary and given freely with a blessing for rest and renewal.”

“Advocate for more co- ordination of job training programs, shopping around for the various employment agencies can be frustrating and time consuming.”

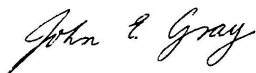
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To Obtain a Full Report: A full report may be obtained from the Schizophrenia Society of Canada, 50 Acadia Avenue, Suite 205, Markham, ON L3R 0B3. Telephone: 905-415-2007 or Email: info@schizophrenia.ca