
QUALITY OF LIFE

As defined by people living with schizophrenia & their families

SCHIZOPHRENIA SOCIETY OF CANADA



QOL SUMMARY REPORT

Prepared by Neasa Martin,
Project Consultant
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QUALITY OF LIFE - SUMMARY REPORT

Schizophrenia can be the cruelest of illnesses. Often striking young people at a critical stage of life when the promise of their future is unfolding. It can bring to a crashing halt the pursuit of learning, thoughts of love and dreams for the future. The symptoms of psychosis can pummel the very core of ones being, confuse the mind, disorient perceptions, and unsettle important relationships with family and friends. So disturbing can its symptoms be that many will hide the cruelty of its impact, withdraw from a confusing, rejecting, and often frightening world to retreat inward. Sometimes alcohol and drugs replace medication with disastrous effect. Family and friends can be left confused and frightened as they struggle to make sense of what is happening, search for answers, hunt for help, rail against the illness or withdraw in despair. Their dreams and hopes for the future may also darken and the quality of life of the family may slip away. But it does not have to be this way. Schizophrenia and psychosis are treatable and recovery of quality of life is possible when people are able to find the right door that opens up options for treatment, support, and hope.

In 2007, the Schizophrenia Society of Canada and its provincial partners revised its mission to focus on “*improving the quality of life for people affected by schizophrenia and psychosis.*” But what exactly does quality of life (QOL) mean? What helps people recover QOL in the face of illness and what can stand in its way? The literature on QOL focuses heavily on clinical issues and adverse events and does not reflect the increasingly important concept of recovery. Recovery in this context does not mean ‘cure’ but being able to achieve ones full potential beyond the limitations of illness. It is taking an active role in creating personal recovery (living life with meaning, purpose and hope), social recovery (meaningful relationships and social inclusion) and illness recovery (managing ones illness through various treatment options). Recovery is about attaining a good quality of life.

In May 2008, the SSC commissioned a Canada-wide survey to learn how it can support people living with schizophrenia and their families to recover the best quality of life possible. Through a qualitative and quantitative survey and cross Canada focus groups, 1,086 people shared what QOL means to them. **Who participated?** Of the 433 consumers surveyed the majority have schizophrenia, are male, single and are living alone in urban centres. One quarter live with their family and 15% live in supportive housing. The average age is 37 years and almost half of participants are employed full or part-time. Most people reported having their illness from 14 to 19 years and have had an average of 5 hospitalizations. Almost all reported taking medications with only 1.4% refusing medications to manage their illness. Ten percent report having a substance abuse or addictive disorder. Of the 570 family/caregivers who participated 80% were female - half were mothers. The average age is 56 years and 74% are married. Thirty-nine percent are currently living with someone with the illness. On average, their loved-one has

had the illness between 14 and 22 years. The vast majority of people are taking medications. Families report between 3% and 8% of their loved ones refuse to take medications. Twenty-seven percent of people with the illness are employed full or part-time. What we learned through this survey is that people living with schizophrenia and their families share similar hopes and frustrations regarding their quality of life. However, there are also some important differences about the meaning and value of QOL. The survey participants provided clear direction to the SCC on the role it can take to enhance QOL. Briefly, here is what people told us....

Hope, optimism and a belief in recovery is critical to QOL

- Overwhelmingly people living with schizophrenia believe recovery is possible. Families know that hope is critical to recovery. But they lose optimism in the face of illness and its losses.
- People living with schizophrenia need their family, friends, and professionals to remain optimistic and to nurture the belief that recovery is possible - particularly when they are ill and their situation feels most bleak.
- Most people believe that the professionals involved in their care share their belief in recovery. Families don't always agree that professionals believe recovery is possible.

Friendships and family support is foundational

- Friendships disappear and some family members are not always supportive when illness strikes. Fear and the harsh judgments of others are painful and contribute to isolation and loneliness.
- The support of a few accepting friends is all that people need. Having a romantic partner is valued but felt by many to be an impossible dream.
- In the absence of friends - families by default are meeting important social needs. Families are also providing valuable emotional, financial, and practical assistance. This enables loved ones to live successfully in the community.

People share similar hopes and dreams for a meaningful life

- But symptoms of schizophrenia get in the way. Purpose comes from meaningful work, feeling connected, contributing to community, having purpose, and being valued. But community is not always welcoming. People want to work but unemployment is common.
- Government-delivered disability pensions are seen as inadequate and unintentionally restrict work, volunteering, and study. This is experienced as discriminatory. Poverty is the unfortunate outcome of unemployment and severely compromises QOL.

Medications and services can foster recovery

- Medications are important to almost everyone and are widely used. However, medications alone do not create QOL - and they can cause additional problems. Most people feel their family and professionals place far too much attention on medication adherence and not enough on what supports recovery and builds their QOL.

- People want to feel respected, listened to, and included in planning decision. They want treatment to focus on their recovery goals and this is often not the case. They recognize that multiple supports enable them to live independently in the community. Often these needed services are not available.
- People want recovery-focused or oriented services. They want to learn skills in medication self-management, ways to avoid crisis and prevent illness. They are asking for practical assistance with housing, employment, income support, and getting connected to their community.
- Where services are absent, families (mostly mothers) carry the heavy burden of care.

Family / caregivers are left out of treatment

- The majority of people want their families involved in their treatment. Confidentiality constraints are the reason given by professional not to include family - but people are rarely asked their preference.
- Families are feeling left out, ignored and criticized by professional service providers. Particularly during times of crisis. This is a major source of stress, which diminishes QOL for both people living with the illness and family.
- Families have their own unique need for information and support and this is not being met.

Finding meaning in the illness helps people to recovery

- The support of peers helps those with the illness and their family understands the illness, build support and learn to cope. Participating in self-help and peer support programs is valued.
- Helping others deal with their illness and educating the public on schizophrenia and psychosis enhances a sense of purpose and meaning. Playing a supporting role empowers people and protects them from the sting of self-stigma.

Creating a balanced lifestyle brings peace and contentment

- People with mental illness are learning how to create meaningful, balanced lives – despite the presence of illness. A balanced life includes work, exercise, leisure, opportunities for learning, spiritual connection, and involvement with community, family and friends. Some people feel creating a balanced lifestyle is challenging and can feel like a full time job.
- People living with schizophrenia are more satisfied with their QOL than their families are. They are learning to live with the limitations the illness may impose. Families want a better QOL and

TOP QOL MEASURES

Being seen as capable - 96%
 Acceptance by family - 96%
 Belief in recovery - 96%
 Peace & contentment - 94%
 Support & information – 94%
 Feeling safe in their community – 93%
 Involvement of friends – 92%
 Medications - 90%
 Hope & Optimism -90%
 Sense of belonging – 90%
 Social & recreational activities – 90%
 Positive relations with professionals – 89%
 Support of family – 87%

expect more for and from their loved one. The slow pace of change and a seeming ‘lack of motivation’ frustrates caregivers, as well as the lack of engagement in shared decision-making.

Family/caregivers need to find balance too

- For families QOL means having time when they feel free from worry. It also means having a job, financial security, friends, and leisure pursuit. Having a supportive partner helps.
- Families often carry a heavy burden. They worry more about their loved one and the possible recurrence of illness, adherence to treatment, social isolation, and poverty than they do about their own needs. As a result, the mental, emotional, and physical health of the family suffers.
- Unanimously families agree looking after their own mental health is critical. Most don’t. Having professional support, learning more about schizophrenia and understanding what supports recovery would help families cope.
- Families need to undertake their own recovery journey to restore meaning and purpose in their lives despite the presence of illness.
- People living with schizophrenia know their families are carrying a heavy load. They want their family to look after their own needs. Families that look after their own emotional needs - help the person living with the illness.

Stigma and discrimination are real barriers to QOL

- People want to be treated as equally as any other illness group. They aren’t.
- Stigma and discrimination are seen as barriers to receiving appropriate treatment options and supports and services that foster recovery of a QOL.
- People feel their basic rights are routinely denied within the health care system. They feel unfairly excluded, unnecessarily feared and harshly judged by health care providers, the media, employers, police, and the community at large. Families agree.
- Treatment, research, and support services are seen as severely under funded. Access to newer medications is limited by cost. Stigma, discriminations, and government indifference are felt to be the cause.

Key Messages For the SSC

Most people, who participated in this survey access provincial Schizophrenia Societies, are satisfied with the services they provide (when available) and want the work of the Societies to expand. They want the Societies to advocate on their behalf in promoting the message that QOL should be better and its improvement is a shared concern. Promoting hope, optimism, and the pursuit of recovery goals are core to enhancing QOL. When people living with schizophrenia have accepting, supportive friends, and family, have an adequate and secure income, are living safely and securely within the community - then they enjoy a good QOL. The Society is being asked to encourage professionals to move beyond a narrow focus on managing symptoms to support and nurture recovery from a body, mind and spirit perspective.

This includes welcoming families/caregivers as partners in care. When services are recovery-focused, encourage active engagement, are hopeful, accessible, flexible, and respectful then professionals play a vital role in helping people create meaningful and purposeful lives despite the limitations the illness may impose. For both consumers and families finding ways to live a balanced, healthy, and engaged life - beyond the illness - vastly improves their QOL.

Recommendations to the Schizophrenia Societies:

- Promote hope, optimism, and the capacity for recovery as key messages.
- Develop recovery-oriented educational resources for people living with schizophrenia and their families.
- Address stigma and discrimination – through education, public policies, and promotion of rights.
- Promote the importance of families as partners in care.
- Align advocacy efforts to maximize QOL outcomes:
 - Make employment a priority – advocate for the removal of barriers (i.e. restrictive government disability pensions) and build bridges to work;
 - Make the support of friends, family and community connections a core emphasis in attaining QOL including peer-support;
 - Advocate for system reform, which aligns with recovery-oriented outcomes.
 - Make the funding of safe, affordable, secure housing a priority.

A Note from Chris Summerville, CEO - SSC

The results of this survey challenge our Societies to not only address the mental illness of individuals but to seek ways to support their mental health needs as well. Consumers and family members want us to advocate for mental health services that address body, mind, and spirit in the context of family and community. Our focus ought not to be exclusively on disease or illness, but on the individual's personal hopes and goals. With appropriate mental health services, focused on recovering quality of life, people can expect to live full lives of meaning, purpose, and connection. We will work with the Mental Health Commission of Canada and all stakeholders to make this a shared commitment!

Full study report and summary data are available on the SSC website <http://www.schizophrenia.ca> All rights reserved. © 2009 Schizophrenia Society of Canada.

Schizophrenia Society of Canada

4 Fort Street, Winnipeg, MB R3C1C4

Tel: 1-204-786-1616 Toll Free: 1-800-263-5545 Fax: 204-783-4898