

QUALITY OF LIFE...

Defined by people living with schizophrenia & their families

Chris Summerville & Neasa Martin
Presentation of survey findings
What did we learn? Where do we go from here?
Implications for the SSC and Health Care Providers
Shared Care Conference May 2009



Purpose of the survey

- Add depth to the 'new' SSC mission.
 - Identify priorities & elements of QOL for people living with Schizophrenia & their caregivers.
 - Inform education, programming & advocacy.
 - Strengthen legitimacy of SSC to speak for consumers & caregivers with government.
 - Inform work of the Mental Health Commission of Canada.

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Review of the literature

- QOL emerged from bio-psycho-social perspective of medicine.
- Used to assess treatment outcomes & justify funding of services → attempts to find a 'scientific' standardize QOL tool.
- QOL is now recognized as a 'subjective experience'.
- Move from 'researcher' defined to 'self- defined' measure.
- Recovery NOT a focus in QOL - is a priority in mental health.
- Family / Caregiver involvement is ignored in QOL research.
- Qualitative research can help define what is important to QOL.

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Survey process used...

- Review of literature on QOL - including recovery literature.
- Interviews with Schizophrenia Society leadership:
 - Developed on-line & hardcopy surveys in French & English.
- Surveys disseminated through SS & other networks.
- Focus groups held with caregivers & consumers.
 - Alberta, Ontario, Quebec & Newfoundland
 - Included Mental Health Commission of Canada leadership
- Preliminary data reviewed with SS community Oct. 2008.
- Summary report with key messages & recommendations.
 - Report and survey data available on the SSC website

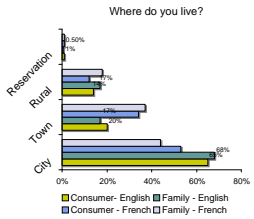
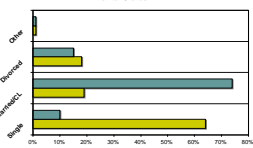
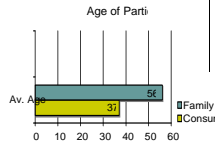
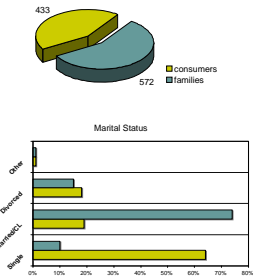
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Who participated?

Number of participants - 1,086
 Cons. 98% completion
 Family 85% completion

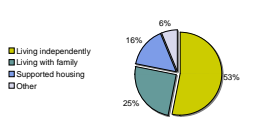


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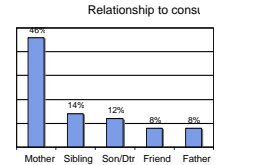
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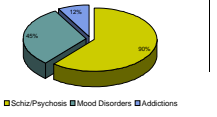
Living situation - Consumers



English average years of illness = 20
 French average years of illness = 14

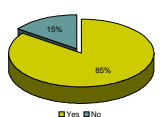


Diagnosis - Consumers



94% English consumers take medications
 85% French consumers take medications
 1.4% Refusing medication

Hospitalization - Average 6 admin.



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What families think is critical



- Families feel their support is **most** important (95%)
 - Unconditional love, non judgmental, calm, patient, providing practical support & positive encouragement.
 - Families are meeting many/ most social & emotional needs.
- Involvement of understanding & inclusive friends.
- Loved one is healthy & safe.
- Purpose & meaning:
 - able to work or go to school; participate in community life; feel accepted; live independently; involved in social & leisure.
- Access to timely medical supports.
 - Families being activity included in care.
 - They are listened to & respected by professionals.
- Live free of stigma & discrimination.
- Many critical factors for QOL are not in place.

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Professional supports critical to QOL



- Multiple supports needed for independence
 - Treatment services (family doctors, psychiatrists, hospitalization, dental care, counseling).
 - Employment services &/or adequate financial support.
 - Housing (safe, decent & affordable)
 - Support for families (emotional support, illness & recovery information & respite).
 - Peer support & self help is critical to both.
 - Community-based supports: ↑ independence, life skills, social skills.... (recovery focused)
 - Support in accessing 'complex' government programs.
 - Healthy 'natural' activities: social, recreational & leisure activities in the main stream community.
 - Faith-based spiritual community involvement.
- Many supports are not available or misaligned.

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Medications & QOL



- 91% are taking medication & rank it as very important:
 - Control of illness does NOT equal QOL;
 - Medications enables QOL → adherence to treatment.
- People are ambivalent about meds (58% feel it limits QOL).
 - Professionals ignore, minimize or don't take complaints seriously (side effects, weight gain & negative symptoms).
 - Many families feel medication complaints are real & ignored.
 - Professionals & families place too much reliance on meds.
- Some families want more legal control & forced treatment.
- Both want access to newer medication - costs covered.
- Both want more research on medications.

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Supports & Services... not just more - but different.



Both want 'recovery-oriented' services.

- Hope & optimism: there's a future - not a life sentence.
- Treated like people - not a diagnosis.
 - Be patient & listen: have concerns taken seriously.
 - Be treated respectfully - as unique individuals.
 - Encourage independence - not dependence.
- Symptom management - not good enough.
 - Deal with multiple losses (trauma, grief, role losses, social exclusion, stigma, loss of hope).
 - Support to achieve **their** own goals.
 - Partners in planning decisions - respect rights.
 - Be practical: help with employment; income; housing; transportation etc.
- Include natural support network (family, friends)

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Limits to QOL - Consumers



- Poverty & unemployment
 - Barrier for pursuing goals, relationships & leisure.
- Social exclusion due to stigma.
 - Most painful from friends, family and professionals.
 - Impacts self-esteem.
 - Experience of discrimination (gov/prof/family)
- Poor health, symptoms of illness, side effects of medications,
- Depression, loneliness, lack of meaning, pessimism of others.
 - Lack of professional support - 1 on 1 (44%)
 - Lack of romantic / sexual partner (33%)
 - Alcohol / drug use (24%), Police involvement (19%)

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Limits to QOL - Families



- Personal impact
 - Burden of care, constant worry, uncertainty, crisis.
 - Frustration & sadness at low motivation/ withdrawal/ ↓initiative. Poor QOL for loved one.
 - Fearfulness for the future (aging parents).
 - Lack of balance - no time for oneself.
 - Negative impact on mental & physical health.
 - Affects family relations - criticism, withdrawal.
 - Financial impact: changing employment, supplementing pensions.

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Limits to QOL - Family



- System failures:
 - Needed professional services - no access or not timely, unresponsive & inflexible. Particularly during crisis.
 - Privacy Act - used to exclude families from care.
 - Huge impact on QOL for families. Feel angry & powerless.
 - 57% consumers want contact with their family.
- Alcohol & drug use → violence.
 - Serious impact on overall family health.
 - Conflicts within family - withdrawal of support.
 - Services do not integrate treatment.

Survey results...



Consumers	WHAT LIMITS QOL <small>Limiting/Significant Limiting</small>	Caregivers
69%	Symptoms of illness	90%
63%	Unemployment/ Insufficient Income	76%
62%	Insufficient income	84%
62%	Side effects of medications	84%
59%	Feelings of depression	86%
55%	Loneliness & Isolation	91%
48%	Lack of purpose & meaning	87%
46%	Hopelessness about future	88%
41%	Poor physical health	72%
35%	Inadequate housing	74%
23%	Alc. & Drug use	73%

Survey results cont...



Consumers	HOW STRONGLY DO YOU AGREE	Caregivers
75%	Recovery is possible	68%
73%	My family is optimistic about my future	51%
72%	I am optimistic about my future	54%
71%	Professionals believe recovery is possible	50%
67%	My family believes recovery is possible	N/A
63%	Enough is being done to support QOL	35%
58%	I am comfortable talking to others about mental illness	75%
49%	My neighbours are supportive of people living with mental illness	24%



Differing perspectives...



- Both share hope and are optimistic for recovery & the future.
- Families see ↑ limitations & ↓ QOL.
- They want more - see not enough being done.
- Families sacrifice their QOL to provide support.
- Consumers have ↑ satisfaction with their QOL.
 - More accepting of illness & its limitations.
 - Building a life - recovering 'new sense of normal'.
- These differences confirmed in focus groups.
- Families are more willing to speak with others.
 - But hold a more pessimistic view of QOL, limitations & needs.
 - May inadvertently increase stigma and discourage recovery.



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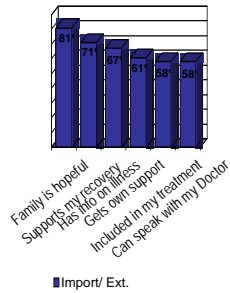
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What consumers want from family caregivers...



- Not all people experience families as supportive.
 - Some have developed their own networks - including peers.
- QOL is intertwined - one affects the other. Care for yourself.
- Need non judgmental support.
- Patience - recovery takes time.
- Consumers also want families to care for themselves.
 - Families need to begin their own recovery journey.



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What is QOL?




- It is much more than illness management & includes:
- The presence of caring, supportive family & friends;
 - Having hope, optimism & a believe that recovery is possible;
 - Creating a life of meaning, purpose, connection & community contribution;
 - Access to timely supports & services that foster independence and recovery;
 - Being seen as people with strengths & capacities;
 - Having the opportunity to work & have financial security;
 - Living a healthy, balanced lifestyle, free from conflict and the symptoms of illness;
 - Safe, secure and independent housing.

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Schizophrenia Societies...

- Majority are / have used SS services.
- SS provide invaluable support - "SS is a lifeline":
 - Timely & accurate information - especially early in illness;
 - Hopeful message is important (can be too pessimistic);
 - 'Families helping families' is critical. Provides support & meaning;
 - Value help in navigating 'the system' which is confusing;
 - SS advocacy with government is highly valued.
- SS not available in many communities (particularly rural):
 - Cost for programs & transportation is a barrier for some.
- Support to consumers highly valued by families:
 - Particularly supported employment & empowerment;
 - Social engagement - serving as a bridge to community.

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SSC role in ↑ QOL

Families want....

- Education:
 - More focus on hope, promoting recovery & schizophrenia;
 - Emphasizing 'early intervention';
 - Fight stigma & discrimination - 'humanize' illness.
- Provision of support: (Calgary)
 - Provide more peer supports, promotes self-acceptance.
 - Build more consumer-focused supports.
 - Promotes recovery, hope & capacity.
 - Teach skills: control illness, independent living.
 - Provide employment/volunteer/social opportunities.
- SS programs must serve as a bridge to the community.

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Messages for SSC

From consumers...

- Recovery is possible! Convey a message of hope & optimism.
- Work is core to our QOL:
 - Poverty & unemployment is an important issue;
 - We want to make a meaningful contribution;
 - Remove the obstacles (pensions) & build bridges to work (peer support).
- Deal with stigma & discrimination:
 - See us as 'people first', not as an illness;
 - Use a positive focus of what we can do not what we can't.
 - Protect our rights - we are all equal, normalize schizophrenia, educate public, address the myths - particularly issue of violence.

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Consumer messages...

Implications for health care providers...

- Medication is important - but QOL is MUCH more:
 - Medications bring both problems & solutions.
 - Too much focus on medications - not enough on QOL.
- Focus more on my strengths - less on my disability.
- Be hopeful. See me as a person first.
- I *need* a variety of support - advocate to align service to meet my goals:
 - Listen more, judge less, treat me with respect & compassion, include me in treatment. Teach me skills - coping, life skills. Support my independence, encourage choice. Help me practically - \$, housing.
- If you help my family - you will help me:
 - Provide families information, practical & emotional support;
 - Educate professionals on my needs & my family's.


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Families want SSC...

- Keep doing what you do. Do more of it!
- Recovery *is* possible - make it a focus.
- QOL *should* be better. *A friend, a home, job, financial security, a say in treatment, good health, quality care, opportunities to contribute & participate in community.*
- Build networks. Reach out into smaller communities.
- Make a bigger tent - create more supports for consumers and include 'natural' caregivers.
- Strengthen the voice of consumers in decision-making.
- Deal with stigma & discrimination - People First - address barriers to inclusion.
- Advocate on our behalf.


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Survey recommendations

- Promote hope, optimism and the capacity for recovery as key messages of the Society.
- Develop recovery-oriented educational resources for people living with schizophrenia and their families.
- Address stigma and discrimination – through education, policies and promotion of rights.
- Promote the importance of families as partners in care.


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Recommendations cont...

- Align advocacy efforts to maximize QOL outcomes:
 - Make employment a priority – advocate for the removal barriers and build bridges to work
 - Emphasize the support of friendships, family and community connections as core to attaining QOL
 - Peer-support plays a valuable role in QOL
 - Advocate for health system reform that aligns with recovery-oriented outcomes
 - Advocate for funding of safe, affordable, secure housing

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Survey strengths/ limitations

<p>Strengths</p> <ul style="list-style-type: none"> ● A FIRST - not done before. ● QOL is an important focus. ● Timely - aligns with SSC goals & MHCC priorities. ● Large sample size. <ul style="list-style-type: none"> ● Canada-wide, urban/rural. ● French & English. ● Long & detailed. ● Excellent completion rate. ● Includes consumers & families. ● Use of focus groups. ● On-line & hardcopy survey. ● Hit SSC target audience. 	<p>Limitations</p> <ul style="list-style-type: none"> ● More time for engaging provincial groups. ● Survey design - less rigorous. ● Not enough focus groups. ● Long & detailed. ● Did not capture important groups <ul style="list-style-type: none"> ● Younger 'First Episode'. ● Aboriginal communities. ● Homeless & hospitalized. ● Ethno-racial communities.
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Questions... Ideas... Comment.
