Session 1

Family Recovery Journey

Participant Notes

Welcome!

Family Recovery Journey is a national program of the Schizophrenia Society of Canada. Its overall goal is to improve the quality of life for families as well as for the family member who experiences psychosis. It is part of a set of family services that includes the Eight Stages of Healing program, family support group, and Name That Feeling children's group.

Educating families has been found to have the following benefits: (Pitschel-Walsh et al, 2001)

- Reduces impact of illness on the family
- Provides tools for family management of illness impact
- Reduces individual relapse rates by up to 20%

We hope that you will find this program useful.

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Program Schedule

Date	Topic
	Overview of Psychosis and Schizophrenia
	Living with Psychosis
	Managing Crises
	Lived Experience and Recovery (guest speaker)
	Building Strengths and Going Forward

Participation Guidelines

Discussion

What guidelines should be in place for you to feel safe and comfortable in this group?

- Confidentiality. Be respectful of each person's privacy.
- Include everyone! Share airtime.
- Avoid side-tracking. If you have questions unrelated to the topic, ask the facilitator at a break or after the session.
- Encourage everyone and listen well. Be supportive of each other.
- Respect differing opinions.
- No pressure.
- Welcome constructive comments.
- Ask permission before offering advice to others or commenting on their needs.

Please be aware that this is a general education program, and the facilitator may not be able to give specific advice on your situation.

Session 1: Introduction and Overview of Psychosis and Schizophrenia

What is Psychosis?

- Psychosis occurs when a person finds it difficult to tell what is real from what is not real.
- It is a set of symptoms that can occur in a variety of situations:
  - Bipolar disorder
  - Clinical depression
  - Schizophrenia
  - Schizoaffective disorder
  - Schizophreniform disorder
  - Drug use
  - Some other illnesses such as Alzheimer's
  - Symptoms are delusions, hallucinations, and problems in thinking and behaviour (see below).
- May be short term, or may last for years, depending on its cause.

What is Recovery? Psychosis is Treatable; Recovery is Expected

Reason for Hope

Many studies have found better-than-expected long term outcomes, with 50-60% of people having significant improvement over time and up to 2/3 being free of psychosis.

- Even people with severe lifelong disability can have significant improvement in functioning and quality of life with modern treatment and rehabilitation.
- "Recovery can be virtually complete in many individuals especially where there are appropriate community-based mental health services." (Spaulding et al, 2017)

A Unique Personal Growth

Pat Deegan is a psychologist who lives with schizophrenia. She says:

- Recovery does not mean cure
- It is a hopeful attitude, a way of approaching the day
- Seeing the person as more than the illness
- Goes beyond rehabilitation – may involve a kind of transformation
- A unique, individual journey

Early Intervention

- Majority of persons receiving early (first-episode) intervention have complete remission within a year
- Early Intervention Outcomes: (Lines & Mulder, 2005; Ehmann, Gilbert & Hanson, 2004)
  - Faster recovery
  - Less family disruption
  - Reduced relapse risk
  - Less risk of damaging social and economic consequences
  - Reduced secondary mental health issues
  - Lower use of hospital and less health care costs

The Schizophrenia Spectrum

Schizophrenia is a psychiatric diagnosis – not a distinct illness but a set of symptom dimensions considered to be on the "schizophrenia spectrum". It affects from 0.5-1.5 of the population worldwide.

Symptoms May Include:

"Positive" Symptoms – delusions and hallucinations

"Negative" Symptoms - Absence of some experiences or behaviours e.g. lack of motivation (avolition), minimal speech (alogia), expressionless face (flat affect), inability to feel pleasure (anhedonia)

Cognitive Symptoms – impaired attention, memory, concentration. Difficulty with planning, decision-making or judgment. Lack of insight or awareness of illness (anosognosia).

Disorganization – disruptions in thought, speech or behaviour e.g. distrustful or suspicious, slow to respond to others, speech is jumbled, inappropriate emotional responses.

Criteria for diagnosis (what must be present in order for the diagnosis to be made):

A. Two or more of the following for at least one month. At least one must be a, b or c.
   a. Delusions
   b. Hallucinations
   c. Disorganized speech
   d. Grossly disorganized or catatonic behaviour
   e. Negative symptoms

B. Impaired functioning in work, interpersonal relations, or self-care for a significant period of time since the onset of the symptoms.

C. Some signs present for at least 6 continuous months. This must include at least one month of active symptoms (unless treated).

D. Other psychotic disorders must be ruled out (schizoaffective disorder, bipolar disorder, depression with psychotic features).

E. The disturbance is not caused by the effects of a substance or another medical condition. https://www.healthyplace.com/thought-disorders/schizophrenia-symptoms/how-is-schizophrenia-diagnosed

Schizophrenia Has Three Phases;

1. **Prodrome** - a period during which changes in functioning occur, prior to psychosis appearing.
2. **Active** - the presence of significant psychosis and inability to function.
3. **Residual/Recovery** - psychosis is greatly diminished or absent. The cognitive dimension has the greatest effect on functioning and the degree of disability or recovery.

Causes of Schizophrenia

The cause of schizophrenia is unknown. It is believed that several vulnerabilities interact. These may include genetics, trauma, prenatal infection, birth complications, abnormal brain development, cognitive impairment, social learning, and/or environmental stressors.

Tips for Communicating with a Person with Psychosis

- PATIENCE! Calm, low key, low pressure and BRIEF
- Parallel (side-by-side) interaction
- Avoid touch
- Do not argue OR agree with delusions
- Remember: this is real and frightening for the person
- Acknowledge experience, state reality
- Distract, change subject or back off if person gets agitated

Symptom	Signs	Strategies
Hallucinations	Signs that someone may be experiencing a hallucination: ◦ Pacing ◦ Restlessness ◦ Increased social withdrawal ◦ Increased sleep ◦ Increased preoccupation with own thoughts ◦ Irritability ◦ Talking to oneself (muttering)	**What Works:** ◦ Provide comfort and reassurance ◦ Lower stimulation in environment (e.g. turn off TV) ◦ Provide distractions such as activities, discussion, relaxation exercises, chores ◦ Empathize with the fear, anxiety or distress **What Doesn't Work:** ◦ Attempts to reason or to debate with the voices
Delusions	Signs that someone may be experiencing a delusion: ◦ Fearfulness ◦ Suspiciousness ◦ Irritability ◦ Restlessness ◦ Pacing ◦ Refusal to maintain routine/ activities	**What works?** ◦ Providing comfort and reassurance ◦ Lowering stimulation in the environment ◦ Acknowledging person's distress ◦ Speaking about how the person is feeling **What doesn't work?** ◦ Debating, reasoning, arguing ◦ Joining in on the delusion ◦ Interpreting the meaning of the delusion
Thought Disorder	Signs that someone may be experiencing a thought disorder: ◦ Confusion ◦ Difficulty communicating ◦ Illogical ◦ Inappropriate emotional response ◦ Pacing, restlessness ◦ Irritability ◦ Preoccupation ◦ Long silences while in conversation	**What works?** ◦ Structuring routines ◦ Limiting behaviour ◦ Using simple words, short sentences ◦ Ask the person to repeat the instructions ◦ • Lowering stimulation in the environment **What doesn't work?** ◦ Providing too many choices

For More Information: Schizophrenia Information Guide (2017) https://www.camh.ca/-/media/files/guides-and-publications/schizophrenia-guide-en.pdf

Biological Vulnerability

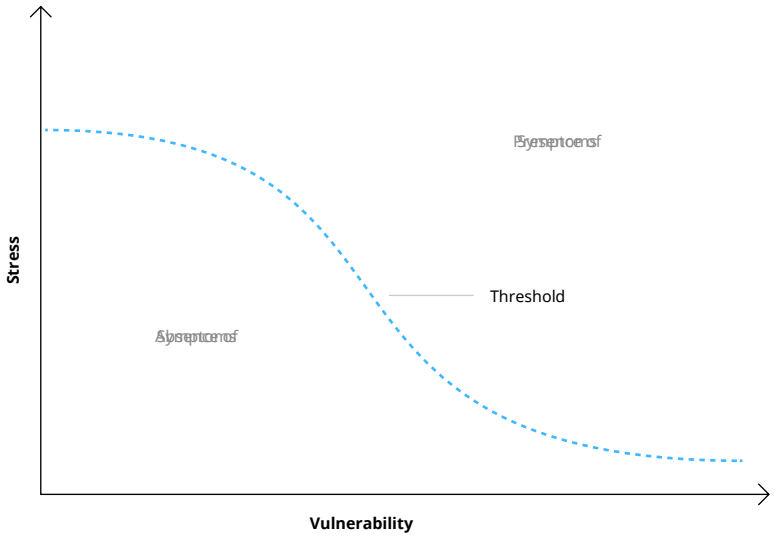
Brain Structure:

- Larger ventricles, more compacted gray matter – brain looks smaller

Brain Function:

- Executive function" of frontal lobe appears impaired (directs other parts of the brain)
- Impaired function of area of brain that regulates stress
- Lack of "silencing" of one half of brain, e.g. when I raise my left arm, only my right brain should be active; in schizophrenia, both sides of the brain remain active

The Stress-Vulnerability Model:



The symptoms are usually first recognized in late adolescence or early adulthood, so it appears to be linked to development. The rate of new cases in Canada is more than two times higher in men. Girls are more likely to be diagnosed at an older age and often do better, which is thought to be due to the effects of estrogen.

Co-Occurring Disorders

Other Psychiatric Disorders

- Depression and suicide. Up to 80% experience major depression, and 20-50% will attempt suicide.
- Substance abuse, addictions
- Repetitive behaviours, obsessive-compulsive disorder and anxiety disorders

Medical Conditions

- Life expectancy is more than 20 years shorter than the general population due to multiple factors such as living in poverty, poor nutrition, smoking, lack of initiative for health care, etc.
- Complications of living in poverty, poor nutrition, unhealthy habits e.g. chronic obstructive lung disease due to smoking.
- Complications of antipsychotic medications: obesity, diabetes, movement disorders, life-threatening side effects.

Myths & Facts About Violence

MYTH: People with psychotic disorders are more violent than other people.

FACTS: 97% of people with mental illness are never involved with the law. Only 3% are involved with the law.

Less than 1% are found Not Criminally Responsible (NCRMD). Of these, only 8% committed violent offences.

Persons with mental illness are less likely to reoffend. The reoffending rate for persons found NCRMD is 7%, while for those with no mental illness in a Federal Correctional Facility it is 45%.

- Higher rates of metabolic syndrome, diabetes and hypertension even before medication treatment. These are often attributed to medication side effects but may in fact be related to the illness itself.
- Some people living with schizophrenia may experience lactose intolerance, celiac disease (gluten intolerance) or underactive thyroid.

Vulnerability

Much more likely to be victims than perpetrators of violence.

Treatment Approaches

Antipsychotic Medications: About 75% of people will have some reduction in positive symptoms. Medications are most effective when given early in the course of the illness.

The quick reference guide to medications (2014) on the next page was downloaded from http://psyd-fx.com/quickreference2014.pdf. Terms used:

- Low Potency – higher doses are necessary to obtain the same response and effect. However, side effects of sedation and weight gain are more common.
- High Potency – lower doses are needed. Side effects of movement disorders are more likely to occur.
- "Ortho" side effects
- Low blood pressure, especially when moving from sitting or lying down to standing (called orthostatic or postural hypotension). These often diminish over time.
- Dizziness and falls
  - EPS = extrapyramidal symptoms (movement disorders)
  - Symptoms that mimic Parkinson's disease
  - Tremor, unsteady gait, muscle rigidity, facial twitching, lip-smacking
- Muscle rigidity can be severe and require emergency treatment
- ACH = anticholinergic effects
- Dry mouth, difficulty urinating, blurred vision
  - Can progress to an emergency – fever, confusion, dehydration

ANTIPSYCHOTICS

NAMES Generic	Brand	Dosage Range [1]	Sedation	Ortho [2]	EPS [3]	ACH Effects [4]	Equivalence [5]
LOW POTENCY							
chlorpromazine	Thorazine	50-800 mg	high	high	++	++++	100 mg
thioridazine	Mellaril	150-800 mg	high	high	+	+++++	100 mg
clozapine	Clozaril	300-900 mg	high	high	0	+++++	50 mg
quetiapine	Seroquel	150-600 mg	mid	mid	+/0	+	50 mg
HIGH POTENCY							
perphenazine	Trilafon	8-60 mg	mid	mid	++++	++	10 mg
loxapine	Loxitane	50-250 mg	low	mid	+++	++	10 mg
trifluoperazine	Stelazine	2-40 mg	low	mid	++++	++	5 mg
fluphenazine	Prolixin [6]	3-45 mg	low	mid	+++++	++	2 mg
thiothixene	Navane	10-60 mg	low	mid	++++	++	5 mg
haloperidol	Haldol [6]	2-40 mg	low	low	+++++	+	2 mg
pimozide	Orap	1-10 mg	low	low	+++++	+	1-2 mg
risperidone	Risperdal	4-16 mg	low	mid	+	+	1-2 mg
paliperidone	Invega	3-12 mg	low	mid	+	+	1-2 mg
olanzapine	Zyprexa	5-20 mg	mid	low	+/0		1-2 mg
ziprasidone	Geodon	60-160 mg	low	mid	+/0	++	10 mg
iloperidone	Fanapt	12-24 mg	mid	mid	+	++	1-2 mg
asenapine	Saphris	10-20 mg	low	low	+	+	1-2 mg
lurasidone	Latuda	40-80 mg	mid	mid	+	+	10 mg
aripiprazole	Abilify	15-30 mg	low	low	+	+	2 mg

[1] Usual daily oral dosage
[2] Orthostatic Hypotension, Dizziness and falls
[3] Acute Parkinson's, dystonias, akathisia. Does not reflect risk for tardive dyskinesia. All neuroleptics may cause dyskinesia, except clozapine.
[4] Anticholinergic Side Effects.
[5] Dose required to achieve efficacy of 100 mg chlorpromazine.
[6] Available in time-release IM format.

Cognitive Behavioural Therapy (CBT): Concerned with the influence of beliefs and thoughts. CBT helps develop practical coping strategies for persistent symptoms. CBT can reduce symptoms as well as provide relief from distress related to those symptoms.

Peer Support and Self-Help Programs: Programs such as those provided by the Manitoba Schizophrenia Society are a valuable part of the recovery journey for many people. Give example.

Family Support and Education: Family education reduces risk of relapse to as low as 20%. Families do not cause schizophrenia, but those who receive support and education can play an important role in their loved one's recovery.

Psychiatric Rehabilitation: this approach sees mental illness as a disorder to be overcome, rather than a disease to be cured. It is holistic, and may include nutrition, art, drama, music, journaling, yoga, or tai chi as well as medications, social skills training, and other supportive activities.

The Future: New Research

- Virtual reality therapy: the person learns to control hallucinations by controlling an online "avatar" https://youtu.be/4Gmp9IILUx4
- Cognitive enhancement therapy: retraining the brain. https://youtu.be/yrYOj9pfEJA
- Personalized medicine: medications are tailored for the individual based on their DNA. – e.g. the Canadian Biomarker Integration Network in Depression (CAN-BIND) program aims to identify objective measures (biomarkers) which will indicate which particular treatment a person will benefit from. http://www.canbind.ca, http://impact.camhx.ca/en/home.php
- "Nutraceuticals": Nutrition is being hailed as the "future of psychiatry". Research shows a number of mental health benefits from nutrition. Some of what we are learning includes:
  - The "gut-brain axis" – problems in the digestive system are linked to problems in the immune system and brain functioning
  - Low levels of Vitamin D and folate have been associated with worsening of psychosis
  - A diet such as the Mediterranean diet is associated with improvement in depression
  - Most of the research is in depression and ADHD: more research is needed in psychosis
  - Diet changes are being prescribed as an adjunct to medication, not a replacement
- More information on nutrition can be obtained at https://ca.ctrinstitute.com/blog/food-for-thought-nutritions-impacts-on-mental-health/

Understanding the Mental Health System

Note: this topic will be addressed in more depth later in the program. Some points to understand now are:

- Every province/territory has its own version of a Mental Health Act. These are similar but may have some important differences.
- The information we are providing does not constitute legal advice.
- Mental Health Law attempts to strike a balance between individual autonomy and the good of the person or community. In the past there have been abuses of power where people were "committed" to hospital for things like being an unwed mother. That is why the criteria are so strict.
- Psychiatrists can only admit a person to hospital if strict criteria are met. This is where your information can be very useful. If you can provide what is called "collateral" information about what you have been observing, that will help the psychiatrist make their decision.

Refer to the handout provided for information on the mental health system in your region.

Working with the Treatment Team

The goal for Canada's mental health system is that it:

- Recognizes families' unique role
- Recognizes families' needs
- Engages and helps families
- Invites families to be partners in care

Tips for Navigating the System

- Familiarize yourself with parts of the Mental Health Act, especially those parts relating to family involvement.
- Find out what the hospital policies are on involvement of families.
- Write a journal with details of your family member's illness.
- Find out if your loved one has a primary nurse and cultivate a relationship with them. They may become your ally.
- Ask your loved one if you can join them when they meet with the doctor or nurse.
- Prepare a list of questions before you meet with the people who are helping your family member. Questions you can ask: https://archive.bcss.org/resources/topics-by-audience/family-friends/2005/06/questions-to-ask-the-psychiatrist/
- Ask lots of questions. Be creative – if you can't get specific information, change it to a general question e.g. instead of "Does she have schizophrenia?", ask "What would we expect to see if she had schizophrenia? How would you treat it?"
- Emphasize those things that you might be doing for your loved one that could be considered health care, and request information to help with that.
- Even if health professionals can't tell you some things, there is nothing to stop you from giving information to them. Ask for an opportunity to give them "collateral information" i.e. your knowledge of your loved one and the background to their situation.
- Suggest to your family member that they consider using a power of attorney for personal care or property in the event that they may become incapable of making decisions about personal care (including treatment) or money and other property.
- Vancouver Mental Health has a Family Bill of Rights: http://www.spotlightonmentalhealth.com/family-bill-of-rights-4/
- To find the privacy law in your region: https://www.priv.gc.ca/en/about-the-opc/what-we-do/provincial-and-territorial-collaboration/provincial-and-territorial-privacy-laws-and-oversight/

References

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