

Leading the Integration of Physical and Mental Health Care

# **Engaging Families in Care: The Case of an Adolescent with Psychosis**

Presented by:

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CONFERENCE FEBRUARY 7, 2020

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Michener Institute



## **Disclosure of Commercial Support**

- This program has not received any financial support
- This program has not received in-kind support
- Potential conflict of interest: none



## **Faculty/Presenter Disclosure**

- None of the presenters in this session have a financial disclosure to report.

# Learning Objectives

- 1) Empathically address mental health stigma amongst family members that directly impact the care of a patient with a mental illness.
- 2) Skillfully address concerns from caregivers regarding psychotropic medications, especially in the adolescent patient.
- 3) Learn about local family psychoeducational services from the Schizophrenia Society of Ontario, and how to refer to such services.
- 4) Learn how to develop an alliance with caregivers that is conducive to greater continuity in care.

# Case Study



The NEW ENGLAND  
JOURNAL of MEDICINE

## Perspective

# Sister First, Doctor Second

Saadia Sediqzadah, M.D.

July 11, 2019

N Engl J Med 2019; 381:108-109

DOI: 10.1056/NEJMp1901489

# Key Messages

## Things we would like doctors to know:

- Include family members as much as you can.
- Support ODSP applications (GPs do not need psychiatric opinion if diagnosis is clear).
- Never underestimate the power of therapeutic alliance and regular follow up.
- Everyone can benefit from CBT for psychosis training, including caregivers.
- Be mindful when referring from the ED.
- Words are powerful.



# Questions?

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# **Engaging Families in Mental Health Care: A Psychiatrist's Perspective**

Presented by:

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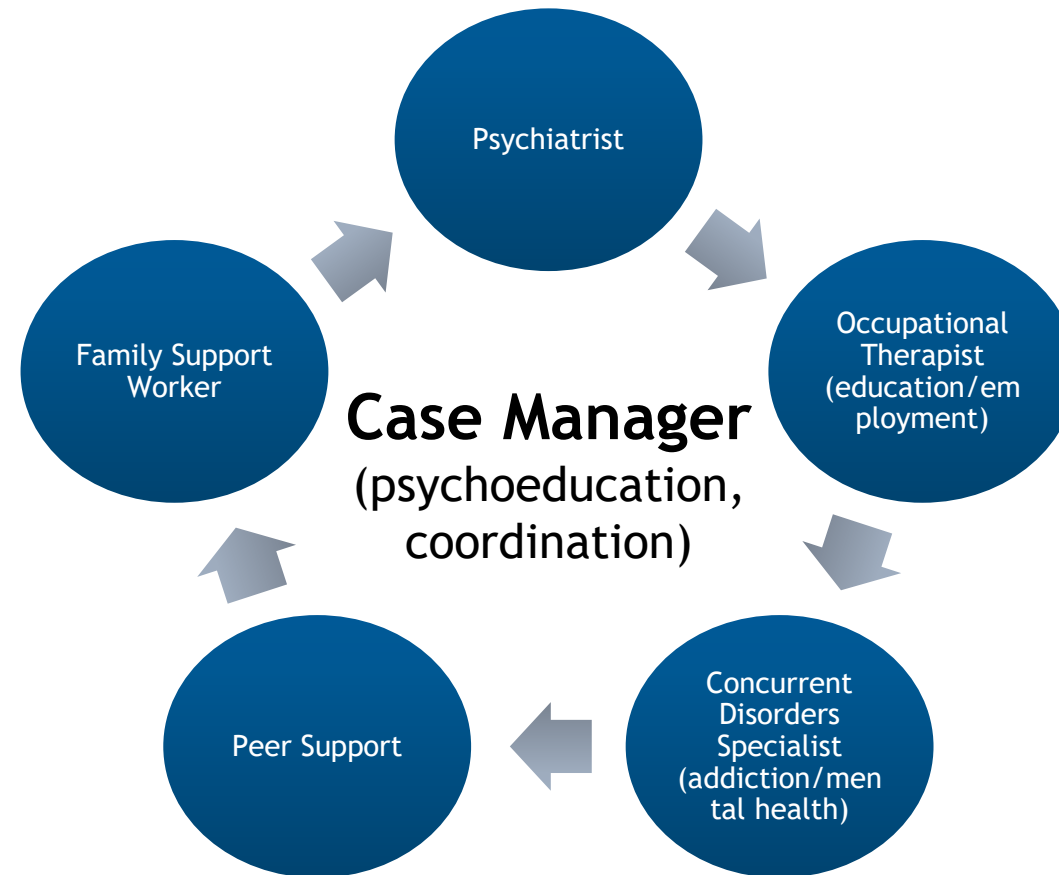


## **Engaging Families in Mental Health Care – A Psychiatrist’s Perspective: Dr. Chloe Leon, MD, FRCPC**

- Staff Psychiatrist at CAMH
  - Slight Centre for Early Intervention, at CAMH, since 2012
  - Early Psychosis Intervention, at CMHA, since 2013
- Assistant Professor, University of Toronto

Clinical population: Young people aged 16-29 with a psychotic spectrum illness (primarily Schizophrenia and Bipolar I Disorder)

# Model of Care in Early Psychosis Intervention (EPI/EI)



# Why Engage Families in First Episode Programs?

## Historical Context:

- Family focused therapy (FFT) emerged in the 1980s and 1990s as a 9-month treatment for patients with Schizophrenia and their families (usually parents, spouse or adult siblings)
- Studies at this time showed medications + family focused therapy = lower rates of relapse and improved social functioning
- Later, FFT was studied in other disorders like Bipolar Disorder with positive results
- An increased understanding of the pathophysiology of these disorders helped families understand that it wasn't the family that 'caused' the illness, but that the illness can be inherently stressful on the family system, which can affect the patient

# Why Engage Families in First Episode Programs?

## Historical Context (continued):

- Studies on High Expressed Emotion (High EE) contributed to development of family-based interventions:
  - Standardized interviews with families were recorded and studied to look for:
    - Critical comments about the pt
    - Expressed hostility
    - Exaggerated emotional responses or unclear boundaries
  - High EE families = 6+ critical comments; evidence of hostility; rated high in emotional over-involvement
  - High EE families were associated across different illnesses (BD, Scz, Depression) to be associated with higher risk of relapse

# Why Engage Families in First Episode Programs?

- Canadian Schizophrenia Guidelines (CJP, 2017):
  - For a first episode of psychosis: include family members (or other caregivers) in the initial assessment wherever possible, with consent from the patient
  - Information from families/caregivers is critical in helping make the diagnosis, but is also seen as an important opportunity to engage not only the patient but the family in the care

# Why Engage Families in First Episode Programs?

Canadian Schizophrenia Guidelines (CJP, 2017):

- Family Intervention should be offered to all individuals with schizophrenia who are in close contact or live with family
- Family Intervention:  $\geq 10$  sessions over 3 months:
  - Communication skills (within the family but also with the mental health care team)
  - Problem Solving
  - Psychoeducation
  - Crisis management and preventing Relapse
- Why? Research says it helps reduce symptoms and reduce hospitalizations

# Why Engage Families in First Episode Programs?

CANMAT and ISBD 2018 guidelines for patients with Bipolar Disorder (BD):

- Family Focused Therapy (FFT) recommended when a patient is both in the maintenance phase (stable) as well as the depressed phase:
  - Outcomes in BD may improve with the support/cooperation of families (especially families with high levels of expressed emotion)
  - Focus: improving communication styles to help relationship functioning
- Why? Research says it helps reduce symptoms and reduce hospitalizations



**Most common questions/concerns that I am asked about  
in my practice....**





# **Most common questions/concerns I receive in my practice\***

1) It was only 1 episode, why does this mean they have a diagnosis?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slight Centre for Early Psychosis

# **Most common questions/concerns I receive in my practice\***

2) Their symptoms are gone, so why can't they stop their medication?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slaight Centre for Early Psychosis

# Most common questions/concerns I receive in my practice\*

3) When will they get better?

- how much better can we expect?
- how long will this take?
- what does the future hold?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slaight Centre for Early Psychosis

# Most common questions/concerns I receive in my practice\*

4) They don't want to take medications or attend appointments with you.....

- Can you do anything about this?
- What can I do to help?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slight Centre for Early Psychosis

# Most common questions/concerns I receive in my practice\*

5) How can you make sure they stop using substances?

- Can you make them stop?
- What can I do?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slight Centre for Early Psychosis

# Most common questions/concerns I receive in my practice\*

6) They are in bed all day and not doing anything. I'm trying to help by getting them up in the morning, but it's just leading to arguments.

- Is this part of recovery or are they just being “lazy”?
- Am I setting enough expectations or not enough?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slight Centre for Early Psychosis

# Most common questions/concerns I receive in my practice\*

7) What's my role in recovery?

- What should I say/do?
- How can I help?
- Will I be informed of progress? How will I know if progress is “on track”?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slaight Centre for Early Psychosis

# Most common questions/concerns I receive in my practice\*

8) I'm scared of relapse.

- What do we do if we notice symptoms again?
- How can we ensure they get hospitalized immediately if symptoms return?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slaight Centre for Early Psychosis



# **Most common questions/concerns I receive in my practice\***

9) How do I respect their wish for privacy?

- I want to know what's going so that I don't worry
- I also need to share what I'm going through with my family and friends for my own wellness

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slaight Centre for Early Psychosis



# **Most common questions/concerns I receive in my practice\***

10) What did I do wrong?

\* Acknowledgments: Harriet Eastman, MSW, Retired Family Worker, Slaight Centre for Early Psychosis

# Key Messages

- Sometimes it can feel that a family is “difficult” – this is when rapport building is even more important – in addition to helping the family by including them, outcomes are better for our patients too.
- Navigating complex family dynamics can be the toughest part of EI – don’t bury your head in the sand - seek support from colleagues and work closely with expert family workers if you can – it’s a long road, but it’s worth it!
- Although confidentiality with our patients is key, helping patients understand the rationale for including families in the care can be an effective strategy to get them on board.



# Questions?

Leading the Integration of Physical and Mental Health Care

# **Strengthening Families Together**

Presented by:

Samantha Wiendels

Family and Individual Clinical Counsellor, RP (Qualifying)

Organization: Schizophrenia Society of Ontario

Alyssa Hirji

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CONFERENCE FEBRUARY 7, 2020

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# Schizophrenia Society of Ontario

- Mission: We make a positive difference in the lives of people, families, and communities affected by schizophrenia and psychotic illnesses
- Programming:
  - Recovery In Acton
  - Ask the Expert
  - CBT-p for caregivers
  - Strengthening Families Together
  - Caregiver Support Group
  - Individual counselling
- Strategic direction: Providing services to individuals and families with chronic mental health concerns



## **Strengthening Families Together (SFT)**

- 4 session group developed by SSO in 2012
- Program aims to provide education, support, and tools for family members and friends of individuals experiencing serious and persistent mental health issues
- Sessions at a glance:
  - Week 1: Understanding Psychosis
  - Week 2: Treatment and Recovery
  - Week 3: Coping as a Family & Self Care
  - Week 4: Mental Health System & Advocacy



**SCHIZOPHRENIA**  

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**SOCIETY OF ONTARIO**  
A REASON TO HOPE

# **SFT – Understanding Psychosis**

- Week 1 formal objectives: Understanding psychosis, system navigation, and how to help as a caregiver
- Week 1 latent objectives: Empower families and instill hope, lower anxiety through understanding, create realistic expectations for assessment / diagnostic process, encourage involvement in care plan



## **SFT – Week 1: Skills and Strategies**

- Identify warning signs
- Develop realistic goals and expectations
- Communicate with circle of care
- Formulate risk and crisis plans
- Create a warm, non-stressful environment
- Assist with life skills and teach positive coping skills
- Model positive behaviour and communication

# **SFT - Treatment and Recovery**

- Week 2 formal objectives: Learning about early intervention, treatment options, recovery, and relapse
- Week 2 latent objectives: How to recognize green, yellow, and red flags over the course of an individual's recovery journey; how to instill hope, strength, and support in care plan

## **SFT – Week 2: Skills and Strategies**

- Facilitate treatment adherence
- Help provide a menu of options
- Identify helpful vs unhelpful safety behaviours
- Support help-seeking behaviours
- Develop healthy boundaries
- Understand system limitations
- Foster a sense of agency and mastery

## **SFT – Coping as a Family**

- Week 3 formal objectives: Understanding feelings of grief, loss, burnout and the importance of self-care, caregiver support, and communication skills
- Week 3 latent objectives: Exercising self-compassion, instituting healthy boundaries, and communicating with open-ended questions, affirmations, reflections, and summaries to increase motivation

## **SFT – Week 3: Skills and Strategies**

- Keep detailed records of events, actions, observation, and interventions
- Become an ally
- Use assertive communication skills – “I statements”; staying present-oriented
- Identify stress – pause – exercise self-compassion – engage in self care – evaluate boundaries

# **SFT – Mental Health System & Advocacy**

- Week 4 formal objectives: Learn crisis prevention and intervention, suicide risk evaluation, and how to navigate the system using advocacy
- Week 4 latent objectives: Empower families to build a toolkit of resources, to know their options, and to advocate for client-centered, strength-based services

## **SFT – Week 4: Skills and Strategies**

- Develop a family crisis plan
- Evaluate safety and risk
- Advocate using system language
- Know rights and responsibilities
- Highlight systemic gaps in service
- Align with stakeholders to effect change



## Question

What is your experience with caregivers as psychiatrists and general practitioners?

What are some of the challenges in interacting with family members?



# Feedback From Caregivers

- Feeling excluded from their loved one's care plan
- Feeling frustrated about early discharges
- Feeling underappreciated
- Struggling with limits of confidentiality
- Overemphasis on medical model
- Viewing patient as a 'case' rather than an individual
- Lack of warm transfer to community supports and services

# Key Messages

- Service providers can support families by:
  - Showing empathy \*\*\*
  - Establishing a therapeutic alliance
  - Actively minimizing power imbalances
  - Treating caregivers as an expert and equal partner
  - Adopting a holistic perspective
  - Validating thoughts, feelings, strengths, and challenges
  - Instilling hope
  - Including and advocating for caregiver involvement in the treatment plan

# Key Messages

- Service providers can facilitate positive communication by:
  - Offering psycho education
  - Providing information about evidenced-based interventions
  - Naming system challenges and gaps in support
  - Outlining what you can and cannot do
  - Providing a point of contact
  - Presenting a menu of options
  - Discussing release of information forms, coordinated care plans, form 1, and form 2
  - Recommending resources – support groups; websites; books; documentaries
  - Providing warm transfer to community services and providing a discharge plan

# Questions?

“Family members who provide care and support to relatives living with mental illness and addiction face a **two-fold challenge**. First, they must suffer with their loved ones through their daily hardships and use their limited personal resources to try to alleviate them. Second, they must contend with a mental health system that often excludes them from involvement in the information-gathering and decision-making processes while simultaneously leaving them to serve as the fail-safe mechanism to provide unlimited, unpaid care, filling in the cracks that open when any part of the so-called system fails.”

*“Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada” 2007*