Discussion Guide
for
out of the shadow
a cinematic study of schizophrenia

This guide is designed for a facilitator working with groups of
MENTAL HEALTH PROVIDERS & TRAINEES such as:
PSYCHIATRISTS, RESIDENTS IN PSYCHIATRY, PSYCHOLOGISTS,
CASE MANAGERS, PSYCHIATRIC NURSES, SOCIAL WORKERS and 
THERAPISTS

Chapter 1: Schizophrenia and the Family
(by Edward Foulks, M.D. Ph.D.)

Chapter 2: Psychosocial Treatment of the “Revolving-Door Patient”
(by Xavier F. Amador, Ph.D.)

Chapter 3: Psychopharmacological Treatment for Improved Patient Outcomes
(by Peter Weiden, M.D.)

Chapter 4: Medical Co-Morbidity and Schizophrenia
(by Ken Duckworth, M.D.)

Chapter 5: Living with Schizophrenia and Recovery: What is Possible?
(by Ken Duckworth, M.D.)
Acknowledgements

My deepest and most humble gratitude goes to my mother, Millie. If it weren’t for her willingness to allow herself to be filmed over 4 1/2 years at her most vulnerable as well as all along her journey toward recovery, then I would not have been able to make out of the shadow. I feel this film is so powerful and instructive because it is so honest. I am also tremendously grateful to my family who were very courageous to share their deepest selves in telling their stories. Each of them did this with the hope that the film would open the door for many other families to find hope and healing.

I wholeheartedly thank Drs. Xavier Amador, Ken Duckworth, Edward Foulks and Peter Weiden, for so generously giving their time to write incredibly insightful and informative chapters for this guide. The guidance and reassurance that each one of them offered me while I was completing the film was very inspiring. At times, their encouragement was the only thing that kept me moving forward toward finishing this extremely difficult project. Each of them believed in the teaching power of out of the shadow before I realized it could have an impact in the professional mental health community.

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Schizophrenia and the Family

In this module, participants will learn:

1) The many ways in which schizophrenia can affect the entire family, not only the patient.

2) The vital, yet often unrecognized, role family members play in successful treatment and recovery from schizophrenia.

3) Increased sensitivity to the experience of family members of patients suffering from schizophrenia.

4) About evidence-based practices for alleviating the suffering of family members and for aiding in their loved one’s recovery from mental illness.

Discussion Questions

After completion of the film’s credits, ask the questions which appear below. After each question you will see points to amplify and develop during the discussion.

1. How did Millie’s mental illness affect her children?
   - What could her husband, other relatives, or neighbors have done to help?
   - What coping strategies and resources are used by each of Millie’s daughters presently?
   - How could mental health providers have done more to protect Susan and Tina?
   - What reporting obligations are mandatory by law for clinicians, teachers, and others?
2. **How did Millie’s mental illness affect her marriage and her husband?**
   - How might Alan’s response to Millie’s illness been more helpful to her?
   - How was Alan affected personally?
   - To what degree was Alan’s response to his wife’s odd behavior and attempted suicide a product of the era (i.e., mid 1960's)?

3. **Discuss the degree of “insight” or “understanding” each family member had and has into Millie’s illness and needed treatment?**
   - Susan?
   - Tina?
   - Tina’s husband Jeff?
   - Millie’s brother John?
   - Their cousin Nancy?
   - Millie’s ex-husband Alan?
   - Alan’s second wife, and Susan and Tina’s stepmother?
   - Millie, herself?
   - How could each family member's knowledge about Millie’s illness been improved?

4. **What role did Millie’s family play in her treatment and progress toward recovery?**
   - In what ways did Millie’s mother hinder and/or help her daughter’s progress toward recovery?
   - In what ways did Alan hinder and/or help Millie’s progress toward recovery?
• What role, if any, did Millie’s brother John and cousin Nancy play?
• What role did Susan and Tina’s obtaining guardianship play?

5. **Why is it that Millie has been in the same home and held a job for more than two and a half years now?**

• What was Millie’s contribution to her own progress?
• What were Susan and Tina’s contribution to Millie’s progress?
• What role did mental health providers play?
• What role did the group home staff play?
• What role did her employer likely play?
Teaching Points for the Facilitator

1) First and foremost, it is vitally important, if at all possible, to utilize the input of the consumer herself in the process of her own recovery. The President’s New Freedom Commission on Mental Health calls for a transformation of the mental health system so that it becomes “consumer and family driven.” The degree of consumer input should be a function of the degree of disability of the consumer.*

2) Those who suffer from the results of mental illness, include not only the person with the mental illness but the family members as well. Millie’s mental illness has had profound effects on her family members throughout the years. For example, her husband could not bear the tension created in the household. He apparently had little information or understanding of the nature of his wife’s illness and that it might have been the cause of her unpredictable moods and post-partum depression. Millie’s brother, John just “checked out” as his way of coping with Millie’s constant disruptions. It is important to recognize the productive and destructive ways in which family members are coping and offer tools to the family for getting help.

3) Millie’s illness left her indifferent and often abusive toward her young children. They carry with them, to this day, feelings of anger and great sadness because of the neglect of the neighbors, their grandmother, and even their own father who all “turned a blind eye” to abuse that had occurred over many years. It is important to consider your role as a caregiver in exploring the circumstances of children in the family.

4) Millie’s qualities of intelligence, wit and a charming personality have a redemptive quality. These qualities have shown through the often dark, harrowing symptoms of the illness. Over time, understanding the difference in Millie’s personality when she’s ill versus when she’s been treated effectively, may have been a huge motivation for Millie’s daughters to devote energy and resources in trying to help their mother find continuity in her treatment and to helping her adjust to stable living in society.

5) Fifty percent (50%) of people with mental illness live with their families.(1) Others, like Millie, transiently move from institutions, to “half-way” houses, from apartment to apartment, and some tragically to the street. In all cases, the illness results in grief, guilt, family disruption and suffering.
Not long ago, families in such turmoil were also stigmatized and blamed for causing or contributing to their loved one’s mental illness. They were accused and corrected by acquaintances and professionals alike as being overindulgent or indifferent; emotionally over-reactive or avoidant; punitive or lax; and critical or gullible. Many family members painfully accepted blame and tried to follow the advice offered, but even more painfully recognized it had little or no affect on them or their ill family member.

It’s important for the mental health professional to help alleviate a family’s sense of helplessness and guilt. Families need to be reassured and guided in their commitment to their mentally ill loved one. False myths, when present, about what family members might have done to contribute to the illness must be dispelled.

Such morbidity in the whole family requires more adaptive responses from mental health professionals and others not only to lessen family burden but also to enhance quality of life for everyone, including the patient. In fact, recent scientific studies indicate that less than 10% of families of outpatients with schizophrenia receive support or education, despite the fact that most mental health professionals believe that such help is very important.

Since the founding of the National Alliance for the Mentally Ill (NAMI) in 1979, there has been an acceleration of studies of various interventions for patients with schizophrenia and their families which have stressed enhancing competencies not pointing out deficits. It took Susan and Tina so many years to figure out how to care for Millie and deal with their complex personal feelings, in large part because they were not offered any education or resources such as NAMI. They had to learn how to care for Millie by trial and error, and completely on their own.

In the last 20 years, a number of approaches to address the needs for family support and education have been developed. They include individual family consultation with a mental health professional, a variety of short term professionally led therapeutic education courses, and family led education and support groups. Under the leadership of the World Schizophrenia Fellowship in 1999, a consensus list of the critical elements of these programs was developed. The list includes 15 principles which have evidence based effectiveness for alleviating the suffering of family members and for aiding in recovery from mental illness of their loved one.
The 15 principles include:

1. Coordinate of the goals and treatment plan of all stake-holders in a collaborative and supportive inter-relationship.

2. Attend to the social as well as clinical (DSM IV) needs of the consumer.

3. Provide evidence-based medication management.

4. Involve family members as partners in planning and delivering treatment.

5. Explore family members expectations of the consumer and of the treatment.

6. Assess family’s strengths and limitations in ability to support the consumer.

7. Help resolve family conflict by being sensitive to their distress.

8. Address feelings of loss.

9. Provide relevant scientific information regarding diagnostic criteria, neuro-pathways, neuro-chemistry, medication actions and side effects, and range of treatment approaches.


11. Enhance effective communication between family members.

12. Train the family in structured problem solving techniques.

13. Encourage participation in family support groups (NAMI, NMHA, etc)

14. Help meet the unique needs of each family with flexibility.

15. Provide direct and secure bridges of referral to other mental health professionals in the event that current work with the family is interrupted or ceases.\(^{(10)}\)
References


3. Constaneda D, Sommer R: Mental health professionals’ attitudes toward the family’s role in care of the mentally ill. Hospital and Community Psychiatry 40:1195-1197, 1989

4. Lefley H: Interventions with families: What have we learned? New Directions in Mental Health Services 62:89-98, 1994


Recommended Resources

NAMI – National Alliance on Mental Illness
www.nami.org
With over 1100 affiliates nationwide, NAMI is a fantastic resource for you, and families with whom you are working. To find out if there is a local NAMI affiliate in your area, see the complete listing on the NAMI National website.

For “Family-to-Family” or “Journey of Hope” family education support groups, contact your local NAMI affiliate office.

Mental Health America
www.nmha.org
www.mentalhealthamerica.net
Psychosocial Treatment
and the Revolving-Door Patient

In this module, participants will learn:

1) The nature of poor insight in schizophrenia.

2) Evidence-based practices aimed at engaging patients in treatment who do not believe they are ill.

3) That there is a critical role family members can play in helping patients to accept treatment and services.

4) How mental health providers can work more closely and effectively together.

Discussion Questions

After completion of the film’s credits, ask the questions which appear below. After each question you will see points to amplify and develop during the discussion.

1. Why do you suppose Millie believed that she was not ill?

   • Was this a defensive coping strategy (e.g., denial)?

   • If so, after more than two years of improvement following her acceptance of both medicine and services (e.g. the supervised group home), why is it that she continues to think she is not ill? Why didn’t she gain insight?

   • Were Susan and Tina able to convince Millie that she has an illness and needs treatment? If so, how did they do this?
2. **Millie ultimately agreed to take medication. Why do you suppose she agreed?**

   - Emphasize the fact that she was NOT being involuntarily treated as an outpatient and ask what other factors convinced her to take medicine on a daily basis.
   
   - What would you predict Millie would do if not living in a supervised setting today? Would she take medication on her own?
   
   - By the end of the film, how did Millie feel about taking medication?

3. **In the years preceding her most recent housing situation and treatment setting, who was more important to her treatment: mental health providers or her family?**

   - During this time period Millie was taking medicine and receiving other forms of treatment on-and-off at her own discretion. What benefit, if any, did she receive from her brief interactions with the mental health system?
   
   - What role did mental health providers play in insuring her safety and that of her children?
   
   - Who ultimately helped to protect Susan and Tina from being “secondary victims” of schizophrenia?
   
   - What role have Susan and Tina played in insuring Millie’s well being and safety?

4. **What barriers kept mental health providers and Millie’s daughters from working together to insure that Millie was receiving treatment, housing and needed services (e.g., occupational rehabilitation, other medical care, etc.)?**

   - Why would a mental health provider not want to speak with Millie’s daughters?
• Over and above HIPPA regulations and ethical considerations, why do you suppose Millie’s mental health providers were generally very resistant to speaking with Susan and Tina?

• What did Susan and Tina do to open up communication between themselves and Millie’s mental health providers?

• What could they have done short of obtaining guardianship?
Teaching Points for the Facilitator

1) A large body of empirical literature published over the last fifteen years indicating that severe and persistent lack of insight in schizophrenia, as Millie exhibited, is usually the consequence of the cognitive deficits associated with the disorder. Most studies implicate deficits in executive, or frontal lobe, function. This research has resulted in expert consensus reflected in the following excerpt of the DSM-IV-TR\textsuperscript{TM}, Schizophrenia and Other Psychotic Disorders section: “A majority of individuals with schizophrenia have poor insight regarding the fact that they have a psychotic illness. Evidence suggests that poor insight is a manifestation of the illness itself rather that a coping strategy. It may be comparable to the lack of awareness of neurologic deficits seen in stroke, termed anosognosia. This symptom predisposes the individual to nonadherence with treatment and has been found to be predictive of higher relapse rates, increased number of involuntary hospital admissions, poorer psychosocial functioning, and a poorer course of illness.”

2) Poor insight, or deficits in illness awareness, is common, affecting approximately one-half of all patients with the disorder (estimates hover around 60%). In addition, as noted in the DSM IV-TR, unawareness of the illness predicts nonadherence with treatment. This should come as no surprise. After all, who would want to take medicine or attend a rehabilitation program for an illness they don’t believe they have?

3) Such problems with insight are very difficult to improve. In fact, despite clinical myth, insight rarely improves with pharmacological treatment.\textsuperscript{ii} \textsuperscript{iii} Meanwhile, psychosocial interventions that utilize techniques of Motivational Enhancement Therapy (MET) --- sometimes referred to as Motivational Interviewing because the technique involves asking the patient questions rather than giving advice or reality testing --- are significantly more effective in engaging patients in treatment who do not believe they are ill. Ironically, MET does not focus on helping the patient gain insight into being ill. Instead, such approaches focus on helping the patient articulate his or her goals and then linking the achievement of those goals to specific treatment and services.

For example, a patient who complains that “No one believes me; no one wants to help me with the conspiracy… I know my neighbors are trying to kill me and I know they’re communicating with each other about me using the pattern of lights they put on in their windows at night…” is not used to
someone listening to this concern without also giving him a dose of reality testing. Sometimes the reality testing is subtle and takes the form of: “So if I understood you correctly, you believe that…” Using terms like “you believe” or “you feel that this is happening” usually alienate the patient making him feel, once again, that no one believes him and must seem to think he’s crazy whenever he tries to talk about the most important thing that is happening in his life (i.e. the conspiracy).

Moreover, this person is not used to someone conveying their respect for their point of view and showing genuine interest in hearing more. Typically, we don’t listen without trying to point out how the belief is delusional. Or, we won’t convey our appreciation and respect for what this person is going through because we are fearful of “colluding” with, or somehow worsening the delusion if we don’t make it immediately clear that we don’t think it’s true. In most cases this worry is unfounded. There is no evidence that one can worsen a delusion by allowing the patient to make the mistake that you might believe it’s true also.

One should never be deceptive and say they believe a delusion is true. Rather, the focus is on not going out of your way to make the point you think the belief is delusional. MET requires that we listen without such corrections and that we convey our respect for the speaker’s experience with empathy while normalizing it: e.g. “anyone would feel that way if their neighbors were trying to kill them.” By actively listening without reality testing, while conveying empathy and normalizing the person’s experience, we form the cornerstone on which we can build an alliance that is based on trust and mutual respect for differing points of view.

One form of MET titled LEAP (“Listen-Empathize-Agree-Partner” in “I am Not Sick, I Don’t Need Help!” by Xavier Amador (Vida Press, 2000) offers strategies for when the time is right to convey your point of view (e.g. this is actually a delusion and you probably would benefit from medicine) and how to do it without damaging the alliance you have built. The overarching goal is to build a relationship characterized by the following:

The person feels that you

1) listen carefully to their point of view and accurately convey your understanding of it

2) respect their point of view and never reality test or offer a contrary opinion unless asked for your opinion several times
3) empathize with them that you would feel the same way were you in their situation

4) think they would benefit from treatment

4) Finally, this relationship is focused on helping the individual discover what is most important to him or her and partnering on those specific goals. In Millie’s case, she wanted a home and a job. MET would focus on linking these goals to accepting medicine and services. But if she were more acutely ill, it could as easily focus on helping her to deal with the conspiracy against her by offering her social support and medicines that would help her handle the sleep disturbance and fear she is feeling because of the conspiracy.

5) Motivational Enhancement Therapy (MET) was first developed to help persons with substance-abuse disorders accept treatment. Interventions based on MET have been found to be affective in patients with schizophrenia who have problems with adherence. In one review of empirical studies aimed at improving medication adherence in schizophrenia, published over a 20-year period, the authors concluded that “…although interventions and family therapy programs relying on psychoeducation were common in clinical practice, they were typically ineffective [with respect to improving adherence]… Motivational techniques, [on the other hand] were common features of successful programs.”

6) Obviously, MET is relevant for all mental health providers working with persons with schizophrenia and related psychotic illnesses. Psychiatrists, psychologists, social workers, psychiatric nurses, law-enforcement officers, case workers, consumer-peer counselors, and residential counselors all have been trained in this approach. In addition, many family caregivers have also been trained. Recently, studies testing the efficacy of motivational interviewing techniques used by psychiatric nurses and family members suggest that persons with varying professional backgrounds can be equally effective in improving adherence. Indeed, one of the advantages of MET training for both family caregivers and “front-line” mental healthcare providers is that there are many more opportunities for interaction than is possible during monthly appointments.
7) Because MET is effective with opportunistic encounters and does not require that one have special “sessions,” it is particularly relevant for family members, assertive community treatment teams, nurses, and residential counselors. Finally, if they exist, maladaptive communication patterns in the family usually are improved when MET is learned, resulting in reduced “expressed emotion,” discord and estrangement.

8) Among the top evidence-based strategies for improving continuity of care, reducing relapse and increasing adherence to treatment is Assertive Community Treatment (ACT), which is sometimes also referred to as PACT. Typically, ACT programs include: interdisciplinary treatment teams with shared caseloads, 24-hour access and mobile crisis teams, assertive outreach to treat clients in their own environments, individualized treatment plans, medication access and support and rehabilitation services. Another hallmark of this approach is the consumer-centered perspective that focuses on helping the patient achieve goals that are meaningful and important to him or her. This is in contrast to programs that are based on the structure of the institutions, such as homeless shelters. Consumer goals often relate to work, housing, and establishing fulfilling interpersonal relationships. In this way, ACT is very similar to MET which focuses only on the consumer’s stated goals and attempts to link his or her desires to treatment and services.

9) There have been approximately 25 randomized controlled trials demonstrating the clinical and cost effectiveness of the ACT program, the most cited study being the Schizophrenia Patient Outcomes Research study (PORT), funded by the National Institute of Mental Health and Agency for Health Care Policy and Research. The PORT study recommended that ACT is essential for individuals who suffer repeated relapse and hospitalization and have trouble complying with treatment. In another paper that reviewed research studies, the authors concluded that ACT reduces hospital time, improves housing stability, improves symptomatology and improves quality of life.

10) Although Millie was not involved in an ACT program when she left the nursing home and entered the group home she lives in today, her daughters Susan and Tina actually performed many of the functions of an ACT program, such as, outreach to where Millie was living and focusing on her goals (e.g. helping her to move out of the nursing home, get a job, live in a house) and insuring she had access to medication and other relevant services.
Finally, the benefit to improving communication and collaboration between family caregivers and mental health providers cannot be stated more eloquently here than it was in the film. The benefit to the patient is typically obvious. And yet, many family members complain bitterly about their inability to work together with their loved one’s providers. Meanwhile, many providers find that family members are a distraction or feel that contact with the family is necessarily a breach of confidentiality: illegal and unethical.

There are several strategies one can use to improve the collaboration that does not require that one act unethically or break the law. For example, patient confidentiality laws and guidelines do not prohibit providers from listening to family members. This strategy is an effective first step to improving continuity of care as the provider has the benefit of information about treatment and other relevant history that they would otherwise never have (e.g. previous serious dystonic reactions to a particular medication, history of elopement from the hospital, of “cheeking”, drug use, etc.).

The provider need not confirm that the person the family member is calling about is a patient of his or hers. One need only say: “I am willing to listen to what you have to tell me about your family member.” Other strategies include insisting that the patient identify at least one family member or close friend that the provider can be in contact with and obtaining written consent.

Finally, family meetings are as vital at admission to the hospital as they are at discharge. An early meeting with family may not only help to plan the course of treatment, but also identify whether any children or other vulnerable persons (such as the elderly) have been affected by the illness (e.g., neglect, abuse, etc.).
References


Recommended Reading


Psychopharmacological Treatment for Improved Patient Outcomes

In this module, participants will learn:

1) The relative advantages and disadvantages of different types of antipsychotic medications in treating people who do not believe they are ill and typically refuse medicine.

2) Strategies for engaging individuals in treatment.

3) The critical role of continuity of care.

4) The role family members can play in breaking the cycle of repeated relapse and hospitalizations.

Questions for Discussion:

After completion of the film’s credits, ask the questions which appear below. After each question you will see points to amplify and develop during the discussion.

1. What kinds of medication were used to treat Millie’s psychiatric condition?

   • What were Millie’s positive symptoms and what medication(s) was she given to treat these symptoms?

   • What were Millie’s negative symptoms and was she prescribed medication for this as well?

   • At one point in the film, Millie was given a mood stabilizer, anti-depressant and anti-anxiety (or anxiolytic) medications. Match the symptoms you saw with the type of medication prescribed.
2. For most of the film, it did not look like the medications worked so well for Millie. If antipsychotic medications are so helpful, why didn’t they work better?

- Millie did not believe she was ill. What role did that play in how well the medicine worked?
- Did Millie’s doctors and mental health workers have an accurate grasp on whether or not she was taking the medicine as prescribed? Why not?
- What could be done (or was done) to insure Millie was taking the medicine she was prescribed?
- If the dose given was inadequate, how could Millie’s doctors have learned that the medicine needed to be increased? Would Millie have been likely to alert them to this?

3. Millie did not like her medications, and it was clear that they made her feel “like a zombie.” Can feeling like a zombie be a side effect?

- If so, what kind of side effect is it?
- What are some of the common side effects of medications used to treat schizophrenia?
- What reasons might Millie have to complain about side effects?

4. In one scene, Mille looked like she was a walking drug store. Why was she prescribed so many medications?

- What are the pros and cons of taking many different medications at the same time?
- Why does the “polypharmacy” occur and what can you do to streamline medication treatment?
5. **Do all of the antipsychotic medications have the same side effects, or are there differences?**

- What are the worst side effects of the antipsychotic medications?
- What side effects are permanent (cannot be reversed)?
- What side effects can be reversed and how is this accomplished?
- Tardive dyskinesia is a very common side effect. Contrary to popular belief, it is not permanent. For many patients it may improve spontaneously without any change in treatment. For others, it may improve with treatment specifically aimed at the problem.

6. **What type of antipsychotic medicine would be especially helpful for someone who has a history of refusing medicine when they need it?**

- How can side effects be reduced?
- Is there a type of medicine that can be given, under supervision, only once every 2-4 weeks?
Cautionary note
The facilitator should start by saying that the discussion does not and cannot be a complete review of psychopharmacology. The goal is to illuminate some important principles that were illustrated in the film and that often do not show up in textbooks.

Getting oriented to the audience
It’s very important that the facilitator understand the perspective of the class/students before starting the discussion on medication management. If the group consists of medical students, psychiatric trainees, nurses, or others with a “biomedical model” background, then the class will likely already believe that medications are necessary for schizophrenia and other serious psychiatric conditions. If this is the case, the focus can quickly move to some of the limitations and challenges of a biomedical model approach. This was especially true when trying to properly treat Millie despite the many barriers to her care. Millie’s case shows some of the basic psychopharmacologic principles in a “real life” situation.

Biomedical background: If the audience has a biomedical model background, then it is likely that, prior to seeing this documentary of Millie:

- The attitude regarding treatment is overly focused on a brain model of schizophrenia, and that medications are the beginning and end of the treatment of schizophrenia.

- They may not appreciate the burden placed on the family to monitor medications, to be the “pill police,” and to be the record-keepers of a mental health system that does not systematically document treatment trials, side effects or outcomes.

- That using multiple medications as seen in the nursing home adds considerable burden on the patient and others in the care system.

- That treatment planning should be measured in years rather than months or days.

- That there are new antipsychotic medications that often work better than older ones, mainly because they have fewer side effects. This tends to give better results due to better adherence.
• While it may not be possible to tell in advance who will respond to which medication, perseverance at the end of the day can make a world of difference in a patient’s life.

**Social work or social service background**: Students of social work or related professions will come away from Millie’s story with a very different point of view than the biomedical model. Hopefully, these days, students will already know that Millie’s illness is not her fault, nor was it caused by her upbringing or her family. However, social workers may feel that because they do not/will not be prescribing medications, that knowing about medications is not very important. For them, Millie’s story is a very valuable lesson in how important it is to know some of the basics about medications, because there were many occasions when a knowledgeable social worker or case manager could have changed things for the better. For this audience, the facilitator should emphasize:

• The synergistic role of working with the system, family and medication.

• The importance of being pro-active in involving families in major medication decisions, as well as seeking their input, and NOT to hide behind the false veil of confidentiality (or, more recently, HIPAA).

• That optimal medication management is only possible when there is continuity of care and often the family is the cornerstone for achieving this.

• The importance of identifying realistic target symptoms and therapeutic goals for medication treatment.

• Knowing basics of treatment trials: **diagnosis**, **drug** choice, **dose**, and **duration**.

• The importance of knowing what the basic medication options are when the medication(s) have failed to adequately treat the symptoms.

**Non-mental health background**: Some participants without any prior medical or psychiatric background may be more likely to doubt the whole concept of the existence of mental illness, and the role of medication to treat mental illness. Here, the facilitator might expect debate about people being allowed to show their eccentricities without being pigeonholed into being labeled as “crazy”, and the concern that the treatment (e.g. medications) may be worse than the “cure”
(docility, chemical lobotomy). Meanwhile, others may see medications as the “silver bullet” thereby ignoring the importance of psychosocial interventions, continuity of care, constructive communication with the patient and health professionals and other vital ingredients to successful treatment.
Teaching Points for the Facilitator

• **Positive and Negative Symptoms:** Psychotic symptoms represent a breakdown of normal cognitive and perceptual functions. There are several ways that psychotic symptoms can present, including distortions of beliefs and ideas (delusions), perceptions (hallucinations), communication (disorganized speech), and behavior (bizarre or grossly disorganized behavior). Often, such symptoms are referred to as “positive symptoms” not because they are “good”, but because they are thought to reflect an over stimulation of normal brain functions. Whereas so called negative symptoms are thought to stem from a loss, or deficit, in normal brain function (e.g., flat affect reflecting a loss in the ability to fully express emotion).

• As the documentary clearly shows, Millie has psychotic symptoms (she loses touch with reality and gets very paranoid about the motivations of others). Students often will have trouble with the boundaries of psychosis, and the facilitator might discuss ways a clinician might figure out whether Millie truly has psychosis. The table below covers some common types of psychotic symptoms and some examples where it may not be absolutely clear whether the person is having a psychotic symptom or possibly could be having a “real” experience.

• **Understanding psychotic symptoms:** Some of the psychiatric disorders presenting with psychotic symptoms include schizophrenia (or diagnoses related to schizophrenia, such as schizoaffective disorder), or mood disorders such as major depression with psychotic features or bipolar disorder. Substance abuse disorders and alcohol disorders are other very common causes of psychotic symptoms.
  *(Note: The facilitator should mention that psychosis is not the same as schizophrenia, but rather that psychotic symptoms are always seen in schizophrenia, but may happen for many other reasons as well).*

• **Antipsychotic medications are powerful medications** and should only be *generally* used for serious psychiatric conditions. Schizophrenia is an illness where antipsychotic medication is needed to control someone’s acute psychosis, such as the breakdowns Millie exhibited, but it is also needed to prevent the psychotic symptoms from returning. The documentary shows that Millie is sometimes, but not always, suffering from a psychotic symptom.
Psychotic symptoms are only a part of the problem in schizophrenia. Symptoms of schizophrenia usually begin during someone’s teens or twenties. People with schizophrenia usually have had symptoms for a long time before finally presenting in a mental health treatment setting. In fact, the average duration of untreated illness is about 2 years! This period of time is called the “prodromal” period. Typically, the person will have non-psychotic symptoms first. Eventually, at some point psychotic symptoms will start. Once psychotic symptoms appear, there is no question that there is a major psychiatric or substance abuse problem, and schizophrenia will be part of the differential diagnosis.
• The core diagnostic criteria for schizophrenia include having positive symptoms, negative symptoms, and cognitive symptoms (e.g., problems with memory and attention).

• Positive symptoms. When psychotic symptoms are a part of the diagnosis of schizophrenia, they are often called “positive” symptoms. These have been covered in more detail in the earlier section on psychotic symptoms.

• Negative symptoms. This refers to aspects of life functioning that are absent or markedly less that expected. Examples of negative symptoms include:
  
  o Apathy. The person has little energy or drive. The person may lie around, stay in bed, and not have any drive or ambition.

  o Indifference. Unlike depression, the person does not care about his or her life situation. There is no sadness, no joy, just numbness.

  o No social life. The person will not have any friends, and will be very socially isolated. There will not be any desire to socialize with others, and the person will not experience loneliness.

  o Poor grooming and hygiene. A person will not care about his/her appearances or hygiene.

• Cognitive symptoms. Cognitive symptoms are not officially part of the diagnosis of schizophrenia, but actually are considered to be one of the major features of the illness. The term “cognitive symptoms”, when used in schizophrenia, does NOT mean mental retardation or a dementia like Alzheimer’s. Rather, it refers to problems learning new information, and specific problems with mental agility

• In general, the antipsychotic medications are more effective for the positive symptoms of schizophrenia than either the negative or cognitive symptoms.
**Recommended Reading**


Medical Co-Morbidity and Schizophrenia

**In this module, participants will learn to:**

1) **Understand the interplay between psychotic illness processes and risk factors for cardiac and respiratory conditions.**

2) **Begin to assess how patient and caregiver education on preventative cardiac care may impact individuals.**

**Questions for Discussion:**

After completion of the film’s credits, ask the questions which appear below. After each question you will see points to amplify and develop during the discussion.

1. **What are the principle medical risks facing people like Millie?**

2. **What barriers exist to quality medical care for persons like Millie?**
Teaching Points:

The increasing recognition that there is a fundamental connection between mind/brain and body has led to a research base that documents increased medical risks for people with schizophrenia and other major mental illnesses. A complex interaction of biologic predisposition, lifestyle choices, self-medication, side effects of newer medications and inconsistent medical care contribute to this risk profile. Medical caregivers are in an excellent if time-pressured position to offer screening and counseling related to these medical risks.

I. HEARTS AND MINDS: INCREASED RISK FOR CARDIAC MORTALITY

Cardiovascular risks are particularly salient for this population. A 2000 study in the Massachusetts Department of Mental Health (DMH) found highly elevated risk of cardiovascular death in the DMH population of persons with severe and persistent mental illnesses. The most common psychiatric diagnoses in these studies were schizophrenia and bipolar illness. People have increased risk for morbidity and mortality from cardiovascular problems as early as age 30, and the risk is persistently elevated across the life span. The relative risk of cardiovascular death was 4 to 6 times higher for the DMH population compared to the Massachusetts age-matched population. It was not possible to identify which common risk factors were more pronounced in the DMH population, but there are many plausible contributing 'suspects', and as they are added together, the risk to the individual becomes progressively greater.

A brief review of common cardiovascular risks and how schizophrenia can interact with them:

a. SMOKING

Research shows smoking helps to address the memory deficits associated with schizophrenia, which is a core deficit in the disorder for most individuals. In this way smoking serves a "self medication" function. Smoking for some also has antidepressant and anti-anxiety effects, at least in the short term. Nicotinic receptors activated by smoking have become the focus of research into the mechanism of psychosis as a result of this finding. Research has also shown motivated people with schizophrenia can reduce and quit smoking, particularly
with the support of a group and nicotine replacement treatment and in some cases buprprion (Wellbutrin/Zyban).

b. DIABETES

Newer atypical anti-psychotic agents (for example: Clozapine/Clozaril, Olanzapine/ Zyprexa, Resperidone/Resperdal, Quetiapine/Seroquel, Ziprezadone/Geodon, Aripirazole/Abilify) have recently been given a "black box" warning by the FDA because of an association with diabetes in people taking these compounds. This risk is thought to be mostly, though not entirely, explained by weight gain leading to type 2 diabetes, which occurs in association with the compounds. The American Diabetes Association (ADA) and American Psychiatric Association (APA) wrote Consensus Guidelines on this important topic. This risk exists on top of a pre-existing risk for diabetes that accompanies schizophrenia--this may be the result of central endocrinologic dysregulation. Preventive strategies related to nutrition and exercise are a key part of the approach to people who face this increased risk.

c. OBESITY

People with schizophrenia are at substantially higher risk for obesity, even before anti-psychotics are introduced. This is likely to be multi-factorial as obesity is an interface of psychology, behavior and physiology. The newer anti-psychotic compounds have been shown to increase risk of weight gain in varying amounts--this is an important consideration as concern about weight gain is now cited as the number one reason for non-adherence to medication regimens. A family history of weight problems or diabetes should be considered when prescribing medications, as the risks of weight gain vary between the compounds. The ADA/APA Consensus Guidelines review the relative risk of weight gain for each of these compounds. People often respond to physician recommendations to exercise.

d. ALCOHOL ABUSE / DEPENDENCE

The mental health field has been slow to appreciate the common co-occurring use of alcohol and other drugs as drivers for psychiatric and medical morbidity and mortality. It is now known in the mental health field that about half the patients with severe psychiatric illness abuse or are dependent upon alcohol or drugs. Service changes are slowly evolving to deal with substance abuse by those with
mental illnesses. Whether the underlying cause is self medication, escape, or deficits in judgment varies from person to person, but this use is thought to be a key contributor to cardiovascular risk. The difficulty in integrating services is also seen from the substance use end of the spectrum: some AA groups encourage people to stop all psychiatric medicines as part of their pledge to sobriety—obviously, this is a grave threat for people with severe mental illnesses. The choice of support groups should be carefully considered--patients should shop for one that meets all their needs, as many are less dogmatic about the use of psychiatric medications. Some locations have "Double Trouble" groups that emphasize adherence to psychiatric treatment and sobriety.

e. STRESS AND DEPRESSION

Clinical depression has been cited as an independent risk factor for cardiovascular morbidity. People with schizophrenia have an elevated risk of clinical depression. A depressive episode often follows for people after their first few psychotic episodes when they come to realize what they have lost. Also, those with schizoaffective disorder have mood dysregulation as part of their illness process and so have increased risk for depressive episodes, and depression commonly accompanies the stress of having schizophrenia. For many people with these illnesses the difficulties in engaging and sustaining supportive relationships compounds their risk as relationships have been shown to reduce stress and the impact of depression.

f. NUTRITION

People with schizophrenia are typically poor. Poverty commonly correlates with poor nutrition. Difficulties in planning and carrying out tasks complicate efforts to shop for and cook healthy, budget conscious foods. Additionally, the service system has been slow to highlight nutritional and wellness oriented strategies for people with serious mental illnesses. Fortunately, there is increasing recognition that some psychiatric treatments may compound this nutritional risk, including elevating triglyceride levels. Proper nutrition and dietary counseling must be better integrated into our mental health culture. This is an area where primary caregivers can lead the way, as they are well versed in advocating healthy lifestyle choices to the general population.
g. LACK OF EXERCISE

Negative symptoms of schizophrenia such as lack of motivation can lead to severely limited exercise. Fortunately, Drop-in centers and Clubhouses are taking a leadership role in promoting activity across the country and this has helped the mental health service system move towards a wellness perspective in serving people with mental illnesses. Physicians are leaders in this area, and over the years have increasingly embraced their role as promoters of exercise. Studies show that when they do advise people to exercise it has an impact.

h. ACCESS TO CARDIAC INTERVENTION

Benjamin Druss, MD has demonstrated that mentally ill people are less likely to get access to angiogram and angioplasty procedures following a myocardial infarction. He concludes that deficits in the quality of medical care correlate with increased mortality for this population. This raises questions about how our medical care system works for people who present behavioral challenges, and challenges medical providers to examine their attitudes towards people with severe mental illnesses.

II. INCREASED RISK OF INFECTIONIOUS DISEASE

a. HIV/AIDS

People with major mental illnesses have a higher rate of HIV infection than the general population, and may, due to difficulties with cognition, need much more support to take antiviral therapies. Simple preventive teaching strategies are essential to reduce the rate of infection for this at-risk population. An important aspect of this risk is a particular vulnerability of some women with mental illness, particularly with co-occurring substance abuse, to be sexually victimized. Another study showed that a substantial subset of sexually active individuals with schizophrenia have traded sex for money or goods, obviously increasing their risk of contracting HIV. Younger and more impaired people had more partners and therefore were exposed to more risk.
b. HEPATITIS C

Dubbed the silent epidemic, Hepatitis C is a growing concern for people with schizophrenia and is often contracted through sex and/or drug use, much like HIV. Hep C can cause serious complications in the liver’s ability to metabolize medications, making drinking alcohol even riskier, and can lead to many long-term problems, including liver failure and liver cancer. New cutting edge treatments are emerging for Hep C, but these have a complex risk/benefit assessment. They can cause depression and suicidal feelings and so must be used with great caution in this population.

III. PROVIDING RESOURCES

Because mentally ill people can be challenging to communicate with, some insurance plans allow extra time and compensation for these patients. In addition to your efforts in primary care settings, resources for people with schizophrenia to address co-morbid health problems can be found at clubhouses and drop-in centers. In many states, a person does not need eligibility into the state’s department of mental health to access cardiovascular education and support through these avenues.

*Hearts and Minds* is a videotape and brochure project illustrating that people with major mental illnesses can improve their lifestyle choices while staying connected to their service system. In the video, real people with schizophrenia and other illnesses discuss their efforts to address the risk factors discussed above. It can be accessed at [www.nami.org](http://www.nami.org).

IV. MODELS FOR BETTER PSYCHIATRIC CARE INTEGRATION

As stated in the President’s New Freedom Commission’s Report (2004), the American health care system is “fragmented and in disarray.” Mental health care is "carved out" as a distinct network from primary care and the rest of specialty care. This often has negative effects on the provision of mental health care and can serve as a service barrier to referrals from the primary care office. This separation has a history in the "asylum" component of traditional inpatient state hospital care--removed from society and medicine--but also more recently in cost-containment strategies and managed care. Mental health services have been
among the most privatized and managed of medical services, but there have been efforts to integrate medical and mental health care. An excellent review of the problem and possible models to promote more integrated care is found at the Judge Bazelon Center’s website (see References).
References

The Department of Mental Health Mortality Study. 2000. www.mass.gov/dmh/reports

Bazelon Center, Get it Together: How to Integrate Physical and Mental Health Care for Persons with Serious Mental Disorders www.bazelon.org

Druss, B, et. al., Quality of Care and Excess Mortality in Older Patients with Mental Disorders, Archives of General Psychiatry, Vol. 58, June 2000.

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Living with Schizophrenia and Recovery: What is Possible?

In this module, participants will learn to:

1) Appreciate the psychiatric fields slowness with conceptualizing recovery and the historical threads that have lead us here.

2) Understand that longitudinal studies demonstrate that many people are capable of recovery.

Questions for Discussion:

1. What do you see as the key elements of Millie's improvement at the end of the film?

2. How might her course have been different if she was engaged in treatment at the onset of her illness process?

3. Is the pessimism that often accompanies schizophrenia justified over the long term?

4. How does the historical framework of schizophrenia inform attitudes towards her recovery?
ESSENTIAL BACKGROUND

A BRIEF HISTORY OF SCHIZOPHRENIA AND IMPLICATIONS FOR RECOVERY

To understand our approach to the possibilities of recovery and better levels of functioning for people with schizophrenia, we must briefly review the historical conceptualization of the illness process and its course. This history, over a hundred years old, is essential to understanding whether we believe (and can design services for) people can improve as they live with this illness. The field was advanced considerably in Western Europe just before the turn of the century, but other theoretical and financial developments have left a complex legacy that hampers our ability to maximize the possibilities for improving the lives of people living with schizophrenia.

When Emil Kraeplin and his colleague Alzheimer divided their fields of inquiry into dementia in younger people (Kraeplin called it dementia praecox--precocious or early dementia) and of elders (dementia senilis--now called Alzheimer's disease) in the 1890s, a great deal was unknown about what it meant to have what we now think of as psychotic illness. Kraeplin interviewed as many patients he could, tried to describe what he saw, and made a substantial contribution to categorizing the illnesses he was seeing. One major contribution he made was recognizing that dementia per se (memory loss and cognitive problems) could impact people who were young and that it was distinct from what we now call manic depressive illness, which he felt was a different illness process. Recently the field has come to recognize, as Kraeplin saw, that cognitive deficits create substantial problems for people with schizophrenia.

Kraeplin made an effort to categorize psychotic illnesses into two major groups: people who had episodic psychosis—in other words, people who were at times very ill but returned to their baseline - and a group with a chronic and deteriorating course which he defined as dementia praecox. This landmark conceptualization divided what is now bipolar disorder from schizophrenia (with schizoaffective disorder as a crossover category). It remains a substantial conceptual leap for the field--that psychotic illnesses needs to be seen and diagnosed over time to better understand the context of the symptoms.

Of the dementia praecox group, his colleague Eugen Bleuler felt there was a need for a better term for this population. He looked for a term that addresses the thoughts, feeling and experiences of the patients as opposed to dementia (memory loss) per se. He coined the term “schizophrenia” (“split-minded” are the
roots of the word) because he noted that patient with this condition had thoughts and feelings that were often mismatched, or "split". Bleuler did not mean split personality (or what is now termed disassociative identity disorder or multiple personality disorder). He was more interested in how a person could describe something sad without looking or sounding sad, for example. Bleuler felt there was a variety of outcomes for the population he termed "the group of schizophrenias".

Kraeplin was a leader in organizing complex presentations into diagnostic frameworks. His poor prognosis group became what are the roots of modern day schizophrenia. Yet he was hampered in his conceptualization by not having longer term follow up with his patients. He also may have viewed the outcomes more negatively because he was seeing the people who were at the hospital—creating a bias towards the more impaired. These factors may have set the stage for his relatively pessimistic view of the condition.

In the decades that followed, the field of mental health/illness became very interested in psychoanalytic work of Sigmund Freud. Over time, people with schizophrenia were often seen through a more psychological lens. An unfortunate application of psychoanalysis produced the phenomenon of "blaming the mother" - a conceptualization that viewed the schizophrenic process as a result of lack of maternal warmth and communication. The idea of the "schizophrenogenic mother" alienated many people from the mental health system, particularly mothers who had other healthy children. Another side effect of psychoanalytic thought applied to schizophrenia is the idea of talking itself as being potentially curative, instead of optimizing coping strategies, including medications. This idea directed many resources away from practical support such as applied work, strategies to accomplish improved living skills, and practical discussion/support of living with a serious illness. These more rehabilitative conceptualizations are now a principle focus of the field, but there has been much time and effort lost in this important area.

The history of the field reveals periods of optimism coupled with complex system and financial changes that contributed to pessimistic assessments of recovery. For instance, the introduction of chlorpromazine (the first antipsychotic agent) in 1954 heralded a treatment that improved psychotic symptoms and inspired much optimism, but the resulting closure of hospitals had deleterious effects. The era of de-institutionalization also was a period of diminished funds for community services. Many people were trans-institutionalized to nursing homes, homeless shelters, and in some cases, correctional settings. There was often poor or no
connection from inpatient state hospital care to a community/family context, which reinforced negative assessments about how much better a person could get.

A modern assessment of how the system of care can connect to a person’s needs and promote a more positive outlook is found in the Presidents New Freedom Commission published in July of 2003. It states "We envision a future when everyone with a mental illness will recover.....and a future where everyone living with a mental illness at any stage if life has access to effective treatment and supports---essentials for living, working, learning, and participating fully in the community." This report’s design for a transformed system of care was based on heavy involvement of people living with the illnesses and their families. It also calls for a system designed to help people’s capacity to "successfully coping with life’s challenges, on facilitating recovery and on building resilience, not just on managing symptoms."

A more realistic and multifaceted vision of how to serve people with schizophrenia is emerging. Yet many are still unsure of what is possible. There may be many factors - family support, cognitive capacity, negative symptoms, pre-existing functioning, gender - that contribute to how people do over time. There is a strong need for research to inform how best to design and implement services to help people with schizophrenia, and this practical field is growing rapidly.

Courtney Harding Ph.D. is a researcher who has developed a more positive view of outcomes for people living with schizophrenia. Her Vermont Longitudinal Study followed 269 people who had been hospitalized for an average of 6 years, then released into the community for an average of 32 years. These people had very strong outcomes: 62-68% were significantly improved, comparing favorably to a less intensively serviced group from Maine. The Vermont program had a focus on work readiness and psychosocial rehabilitation. Maine's system was less rehabilitative and the outcomes for this group were less robust in terms of work, functioning, and symptoms. The Vermont study remains hallmark in demonstrating that a rehabilitation focus can improve long-term outcomes for people living with schizophrenia.

Yet even without focused rehabilitation, many people with schizophrenia accommodate to the illness process and find their symptoms diminish over time. A review done by Harding notes 5 long-term studies from different eras and countries. Of these studies, she concludes "One-half to two thirds of nearly 1200 patients followed over two to three decades significantly improved or recovered." Definitions of significant improvement/recovery differ between the studies and there are methodological differences between them, but in aggregate they represent the radical idea that getting better is a likely path. One of the
researchers was Eugene Bleuler's son, Manfred, who followed people from the Burgholzli Hospital consecutively admitted from 1942 and 1943. He tracked only people with true schizophrenia, eliminating other conditions, following them for decades, and concluded, "I have found the prognosis of schizophrenia more hopeful than I considered it to be."

This film beautifully illustrates what recovery can look like. Millie benefited from her devoted daughters who would not take "no" for an answer, and the system which finally matched her needs with a placement suited to her. With their help, she found some symptom control, a place to call her own and got help a job she enjoys. This outcome reclaims her dignity and improves her quality of life, which is for many the definition of recovery. NAMI has developed a supportive and educational curriculum for families and taught by families learning how best to cope with and help their relatives. The program, called Family-to-Family has groups in every major American city.

What are the prospects for recovery for people who do not have such family support, or for people who have additional risks such as substance abuse, poor medication adherence or medical concerns? While outcomes vary considerably, education and advocacy can help to make these illnesses better understood and less stigmatized, thereby reducing the long delays in help seeking, as seen in this film, Out of the Shadow. The improvement in understanding we are seeing in this country comes at a time of reduced budgets and service cuts and so the need for advocacy has never been stronger. This film and your efforts are part of this important social movement.
References


Harding, C. et. al., The Vermont Longitudinal Study of Persons with Severe Mental Illness II. Long Term Outcome of Subjects who Retrospectively Met the Criteria for DSM-III Schizophrenia. American Journal of Psychiatry, 144 (6) 718-726.

