

## **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 Kraepelin and his colleague Alzheimer divided their fields of inquiry into dementia in younger people (Kraepelin 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. Kraepelin 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 Kraepelin saw, that cognitive deficits create substantial problems for people with schizophrenia.

Kraepelin 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 “schizo-phrenia” (“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".

Kraepelin 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 President's 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 of 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**

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