Treating a Person Living with Schizophrenia

a Discussion Guide for Primary Care Providers
to accompany the documentary

out of the shadow

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This guide is designed for use by the following audiences:

FAMILY MEDICINE, INTERNAL MEDICINE,
EMERGENCY ROOM PHYSICIANS, NURSES,
PHYSICIANS ASSISTANTS, ALLIED HEALTH PROFESSIONALS
and TRAINEES
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Chapter 1

Primary Care: An Unexpected Front Door

Goals for this chapter include:

1. Gaining an appreciation for the complex social forces that lead people to seek help late and in the primary care setting.

2. Understanding how stigma impacts caregivers as well as care receivers.

Questions for Discussion:

1. How are the coping styles of members of Millie’s family different from and similar to those found in caregivers you have worked with when faced with psychiatrically ill people?

2. What can primary care providers do to enhance detection of serious and life-threatening psychiatric illnesses like Millie’s? What are the main barriers to detecting psychotic disorders?

3. What are the avenues and obstacles for a person like Millie to get help today? How is this similar to and different from the film's era?

4. Would a child abuse/neglect petition from a mandated reporter have made a difference in accessing services for this family?
TEACHING & DISCUSSION POINTS

I. EVERYONE TRUSTS THEIR PRIMARY CAREGIVERS

In general, people trust the knowledge and wisdom of their primary care doctors and nurses. That trust combined with the fact that psychiatric conditions often generate somatic symptoms are why physicians, nurses, physician assistants, and even physician’s secretarial staff are often the first stop for a patient or a patient’s family member when seeking information and guidance about severe mental illnesses such as schizophrenia, schizoaffective disorder, bipolar disorder, depression, or other psychiatric disorders. Even though as a physician, you may have had incomplete exposure to people living with major mental illness in your medical school or nursing training, patients who are dealing with a desperate situation, either in their own lives or with their loved ones, will turn to you because you have helped them in the past. It takes great trust for someone to share the vulnerability and helplessness they may feel in discussing mental illness with you. When a family like Millie’s seeks help, you can be a key resource for them whatever your level of experience with mental illness. Out of the Shadow and this discussion guide can provide perspective on this important and often overlooked area of medical practice and give you some resources for support and referral that you can pass along to individuals and families contending with mental illness.

II. LACK OF INSIGHT: A CORE FINDING OF SCHIZOPHRENIA

Barriers to getting help often begin inside the person’s own psyche and are then mirrored in and magnified by the struggle to access services in the mental health system. Many people with schizophrenia, like Millie, completely reject their diagnosis. These patients are not "in denial" in a psychological sense - the neurologic term anosognosia is a better fit for the clinical reality. When a person feels nothing is wrong, there is naturally little motivation to seek help. Xavier Amador's research has demonstrated that about 60% of people with schizophrenia do not perceive their experience of voices, paranoia or delusions as part of an illness process.

The Surgeon General’s Report on Mental Health concluded that many people, and minority populations in particular, view their primary care provider as their only mental health provider and resource. This increases the chances that the issue may be brought to your attention by someone in the family, if not by the patient himself. Primary care providers provide much
of the mental health care in America, but are frequently under-recognized for this important contribution.

III. COMING IN THROUGH THE “WRONG” DOOR

Given the financial constraints and lack of coherence of the current mental health system, many people access mental health care through alternative doors: primary care, as I have suggested, is the most likely. A recent expert panel convened at President Bush's request has called the system a "shambles" and a "patchwork relic". Often, people with psychotic illness and poor insight find their way to the mental health system through a more problematic door - as a result of interactions with police and other criminal justice personnel. When people arrive in jails or lock up for petty crimes or disorderly conduct driven by untreated illnesses, they often enter the mental health system via medical caregivers who are involved in the criminal justice system.

IV. WAITING FOR HELP, FIGHTING FOR SERVICES

Families of those with severe mental illness are typically unprepared for the psychiatric crises that confront them. As was so effectively demonstrated in the film, it can take decades of battling to get access to services. And often these services are perceived as patient- and family-unfriendly. The 2005 National Co-Morbidity study funded by the National Institute of Mental Health demonstrated that excessive delays in service are the rule rather than the exception---waits of 8-23 years are described for anxiety disorders, 6-12 for depressive disorders. The study did not address schizophrenia, but given the lack of insight that can accompany the disorder, it can be presumed that the delay for those seeking help with it would be much longer still. Family-led resources like NAMI's Family-to-Family course reduce the isolation and self-blame so often experienced by family members and help them to actively plan for a more positive outcome.

V. SOCIETAL DENIAL

In the film, Tina's suicide attempt was the unintentional catalyst for Millie finally getting a diagnosis for her disorder. But the fact that 12-year-old Tina was driven to such a desperate act represents a collective societal failure in dealing with Millie's illness. Stigma - the negative societal valuation placed on psychiatric illness - causes many people to avoid seeing what is in front of them. This is in a sense a kind of "social anosognosia". No one wants to
have or know anyone who has a severe mental illness and few people feel comfortable discussing it because it may elicit shameful reactions. A physician’s office is one of the few places where a person like Millie can be perceived clinically, as a person struggling with a psychiatric condition. The tendency for the patient to view medical caregivers through the paranoia of the disease can complicate the caregiver's role but does not lessen its importance.

VI. EARLY DETECTION

The film does not discuss whether Millie had regular physical exams or medical follow up. Lack of access to specialized mental health care services, as well as a poorly organized referral process, act as disincentives to those seeking help. Recognizing the presence of mental illness and referring the patient to the appropriate services is a profound contribution that primary caregivers can make. There is a body of evidence suggesting that early intervention in the diagnosis and treatment of psychiatric disorders generally leads to a better overall outcome for the patient. Based on this evidence, initiatives have been developed to promote the recognition and improved treatment of depression in primary care settings.

VII. AVOIDING PEOPLE WHO HAVE MENTAL ILLNESSES

In the film, several people withdraw from Millie. Her ex-husband appears overwhelmed and under-informed. Her cousin feels relieved by the end of their visits. Both are unable or unwilling to imagine Susan and Tina’s experience as children, in spite of their own clearly negative responses to Millie’s behavior. The desire to avoid contact with an actively psychotic person is understandable - the illness is at times terrifying and we do not understand it very well. In a best-case scenario, the role of the primary care clinician can be as an active liaison between the patient and/or family member and the mental health service. When the trusted medical provider introduces the person to the mental health clinician, a stronger connection is generally made. If your most honest reaction to your patient is avoidance, then use that as information to inform you of the person's profound internal distress. This could then inform a referral to a mental health practitioner to assess the person’s disorder, determine appropriate outreach, assess family context, offer constructive supports, and attempt to engage the patient in services.
VIII. DIAGNOSING SCHIZOPHRENIA

Ruling out many possible medical causes of psychosis requires investigation into neurological, infectious, and metabolic avenues. When these have been eliminated, the diagnosis of schizophrenia requires an active psychotic process (e.g. hallucinations, usually auditory, or delusions and fixed false beliefs) that is sustained for more than six months and coupled with a decrease in social and occupational functioning. Your index of suspicion for psychotic illness should be raised when there is inconsistent or bizarre behavior, isolation, contradictory or poorly articulated history, trouble holding a job or maintaining relationships, and/or active substance abuse—these are functional deficits that are not specific to, but are commonly seen with, untreated schizophrenia. The early diagnosis can easily be overlooked if there is a hallucinogen or other substance being used. This may explain some of the symptoms, or if there is avoidance, or absence of medical care. Women typically have a later onset of their condition than men—mid-20’s is the median age of onset for women, with a distribution across a decade. The distribution is about 5-7 years younger for men.

IX. THREE CORE SYMPTOMS OF SCHIZOPHRENIA

Recent conceptualizations of schizophrenia currently define three core symptom areas, with the proportion of symptoms differing considerably among individuals:

a. **positive symptoms**: hallucinations, delusions, paranoia

b. **negative symptoms**: lack of motivation, flat affect, interpersonal deficits

c. **cognitive symptoms**: executive functioning, verbal and working memory deficits, learning new information

This framework is not part of the DSM framework for diagnostic criteria but it is increasingly how clinicians conceptualize and target different symptoms. As a rule, anti-psychotic medications are more effective for positive than negative symptoms. Rehabilitation strategies address negative symptoms, but negative symptoms are often difficult to impact. Millie demonstrates components off all three types of symptom complexes.
X. THE “SCHIZOPHRENIAS”

Many researchers and clinicians believe the condition should really be called "the schizophrenias" as the constellation of symptoms for different individuals can vary considerably from one person to the next. Interestingly, recent research suggests that positive symptoms do not prevent people from employment, but deficits in cognition frequently do. This has led to a recognition of the need for better agents to enhance cognition and learning at the National Institute of Mental Health level and also for changes at the service delivery level. Occupational training, for instance, has shifted from sheltered workshops to more of a spectrum of employment support: people get more motivated for "real work", as Millie demonstrates so well at the end of the film when she talks about her new job at the bakery.

XI. CHILD ABUSE AND NEGLECT

Obviously, Millie was incapable of consistently providing a safe environment for her children, but no one in her family or her community reported this fact to anyone in a position of authority to help Susan and Tina. It is critical that all mandated reporters of suspected child abuse and neglect, including any primary caregivers, be extremely vigilant when dealing with mental illness in the context of a family with young children. Since the 1961 paper, “The Battered Child Syndrome,” was first published, all states have adopted mandatory reporting statutes. Persons with major psychiatric illnesses who are in treatment are often able to parent effectively, but untreated psychotic illness is a high risk factor for child maltreatment, particularly if the patient is, like Millie, a lead or sole parent. Primary care providers are often the first to be in a position to assess the child's safety. Should you decide to file a report of suspected abuse or neglect, it is crucial that you find a moment of your scarce time to review your decision with your patient (the parent). Though this can be unpleasant in the short run, it best serves the needs of your patient and their children in the end.

XII. USING E.R.s FOR MENTAL HEALTH SERVICES

A subset of people with schizophrenia use Emergency Rooms as their defacto treatment facility. This adds to the pressures on that scarce resource. This may be because they cannot organize themselves to make and keep regular appointments with a physician, or it may be because undetected and untreated conditions often demand more urgent attention when psychotic episodes occur. ER settings typically have some mental
health resources. It is important for patients to connect with a social worker or psychiatrist in that setting to facilitate evaluation for services.

Contacts with mental health outreach services may help to prevent overuse of the ER. These strategies have also been demonstrated to improve the quality of medical care for people with major mental illnesses. Services that may be accessible to people who use emergency services as primary care include mobile crisis services, Assertive Community Treatment (ACT or PACT), or intensive case management. The mental health service culture has evolved to focus on serving people in community settings with outreach as opposed to isolating consumers in state hospitals, formerly called asylums. But the gaps in this new system have resulted in everyone from people in the criminal justice system to homeless shelters to emergency room staff who are now actively involved in dealing with people with major psychiatric illnesses. Advocacy for more comprehensive services is increasingly becoming a part of Emergency Service work as without better services, ERs will continue to be overused by the psychiatric population.

XIII. ADVOCACY GROUPS: A NATURAL PARTNER

Because primary care providers and emergency room caregivers are burdened with the "downstream" impact from the under-funded and over-taxed mental health service system, you are natural allies for mental health advocacy groups. Without a voice for better and more services, primary care and emergency settings will continue to inappropriately provide care they are not funded for. Across the nation, it is not uncommon for people with major mental illnesses to wait for days in emergency room for a placement disposition. This is unethical both for the person and for the resources misspent to hold them without intervention. Fortunately, advocacy groups like NAMI are working to change this reality. The National Alliance for the Mentally Ill has a national campaign to join with the parties inappropriately impacted by the failed mental health system. Called the Campaign for the Mind of America, ER doctors and primary care doctors join county jail administrators, police chiefs, homeless shelter directors, and school leaders to decry the misallocation of resources that result from the failure to adequately serve people with mental illnesses. The campaign has held press conferences in multiple states and has successfully fought inappropriate system cuts that would worsen this problem.

NAMI has nearly 1100 affiliates across the country. Together with the American College of Emergency Room Physicians, NAMI has created resource guides for consumers, family members and ER doctors to better
support people who are in ERs after suicide attempts. For more information on this collaboration or on the advocacy and educational efforts of NAMI see www.nami.org
REFERENCES


*ER Guide for Families*
www.nami.org

Goals for this chapter include:

1. Understanding the interplay between psychotic illness processes and risk factors for cardiac and respiratory conditions.

2. Beginning to assess how education and caregiver focus on preventative cardiac care may impact individuals.

Questions for 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 & DISCUSSION 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 schizo-affective 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 INFECTIOUS 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 though 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

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).
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Chapter 3

Living with Schizophrenia and Recovery: What is Possible?

Goals for this chapter include:

1. Gaining insight into the psychiatric fields slowness in conceptualizing recovery and learning about the historical threads that have lead us here.

2. Gaining a cursory understanding of the longitudinal studies which 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 “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".

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.
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