MENTAL HEALTH
Fighting the Stigma

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www.socalphysician.net February 2011
Mental illness is every bit as serious as heart disease or diabetes, yet it often is not treated on a par with those conditions. Here are the basics.

When 22-year-old Jared Lee Loughner opened fire at a political meeting in Tucson in early January killing six people and injuring twenty, a stunned nation asked “Why?” Why didn’t someone realize that Loughner was dangerous? And if they did realize it, why didn’t they seek help for him?

Similarly, after 23-year-old Seung-Hui Cho killed 32 people and wounded many others before killing himself in a shooting massacre on the campus of Virginia Tech in April 2007 it was revealed that he had a history of mental instability. Worse, several professors had reported disturbing behavior and he had been investigated for stalking two female students. Why didn’t anyone connect the dots? Why wasn’t he being treated for mental illness? Why was he allowed to be the architect of the deadliest shooting incident by a single gunman in United States history, on or off a school campus.

All good questions, albeit ones that are not easy to answer. When it comes to mental illness treatment, there’s a tangled web of complications. The list ranges from the stigma, shame, and isolation that sufferers and their families may feel; there’s a lack of education and training for recognizing symptoms—and knowing what resources are available for help; there’s the cyclical nature of the disease, making it hard for physicians to diagnose; there are issues getting patients to comply with treatments; there’s lack of insurance coverage; there’s discontinuity of care; and sometimes there are complicating issues such as substance abuse.

The issues surrounding treatment for mental health illnesses are so vast and complex that we are able to only touch on some of the key concerns in this article—most of the issues surrounding stigma and parity. Entire articles could easily be written on subsets on the issues—for example, mental illness in adolescents or different ethnicities, mental illness treatment in the prison and jail systems, treatment for military personnel and much, much more. So, while this article is by no means definitive, hopefully it will give you a small taste of what your patients and psychiatrist cohorts are possibly up against.

BY CHERYL ENGLAND
Julia's Story
Julia Robinson Shimizu's story illustrates many of the points about what is wrong with mental health care in the United States. Seven years ago Shimizu's 18-year-old son “got sick” shortly after the start of his freshman year in college. He stopped eating, stopped talking and stopped going to classes. The college sent him home, stating that he needed clearance from a physician to return. “I was literally on my knees begging him to please go see a therapist,” says Shimizu. “He wouldn’t go. But since he wanted to go back to school, I had that on my side.”

Since the school did not require clearance from a mental health professional, Shimizu's son went to his childhood pediatrician. “When he went to the pediatrician his health was OK and he was doing well enough to be articulate,” continues Shimizu. The pediatrician cleared him to return to school—where he promptly fell apart again.

In a twist of irony, Shimizu decided to go to a therapist to help her deal with her son’s problems. The therapist was the first person to diagnose her son as schizophrenic based on her descriptions of his symptoms. Even then, Shimizu and her husband struggled for years to get help for her son—and to get him to accept that he needed it. Resources and help were difficult to find. Insurance wasn't willing to pay for treatment. “We got a very nice letter from our private insurance company,” says Shimizu. “It said they'd be glad to help once my son was medication-free and symptom-free for 5 to 10 years. I had even heard of insurance providers who limited other families to six sessions with a therapist—that won't get you far.”

Eventually, their son's doctor helped Shimizu apply for Medi-Cal funding. And she was directed to NAMI, the National Alliance on Mental Illness, where she currently serves on the Board of Directors. “It was a horrible time. We were so lost,” says Shimizu. “NAMI offered help and support.”

Now, at 25 years old, Shimizu's son has been in treatment for a bit over a year. It's been a very, very long journey,” says Shimizu. “He's now very compliant with his medication. But medication alone won't do the trick. Medication and talk therapy is known to be effective. When a person gets ill, they lose lots of years—talk therapy can help.”

Lag Time
Unfortunately, Shimizu’s story is more the rule than the exception. “The real tragedy is that we don’t recognize mental illness early in the onset,” says Rusty Selix, Executive Director and Legislative Representative for the Mental Health Association in California. “On average, it is six years after the onset of a mental illness before it is identified and a treatment set.” Eerily true to form, it took six years for Shimizu to begin getting treatment for her son.

More than 20 percent of the U.S. population—44 million people—experience a mental disorder in any given year, but almost half of these individuals do not seek treatment according to a 2002 report from the U.S. Department of Health and Human Services, 2002. “My son would sometimes stand in the middle of the kitchen and say ‘Thoughts, thoughts, thoughts are going by and I can’t catch them’. He knew something was wrong but he was still resisting help,” she says.

Without treatment, people with mental illness develop additional problems—and develop them faster than do people without a mental illness. One Medicaid survey, for example, showed that people diagnosed with mental illness have five times the rate for all major illnesses—diabetes, hypertension, and heart disease—than those without a mental illness. And, according to the Centers for Disease Control and Prevention, people who suffer from chronic, untreated depression may die up to 25 years earlier than the average lifespan.

Untreated mental illness is also costly. Serious mental illnesses cost $193.2 billion in lost earnings per year, according to findings in a 2008 issue of American Journal of Psychiatry. And people with untreated mental illness are swamping emergency rooms, straining the system. Out of 95 million visits made to emergency rooms by adults in 2007, 12 million, or 12.5 percent, had to do with mental disorders, a substance abuse problem, or both according to a recent report from the U.S. Agency for Healthcare Research and Quality. Of those 12 million visits, about 66 percent involved patients with only mental disorders. Almost 41 percent of those 12 million visits resulted in the patient being admitted to the hospital, which is more than 2.5 times the rate of hospitalizations for other conditions.

The Stigma Sticks
Most mental health experts agree that the stigma attached to mental illness is a key reason that more people do not get help. “There is huge discrimination against people with mental illnesses,” says Selix. “What can we do to change the stigma associated with mental illness? We don’t have the answers.”

While Shimizu's son is on a good path currently, the family's ordeal is still not over. Feelings of shame still linger. “For the longest time we didn't want to tell anyone,” says Shimizu. “My husband still has people he hasn't told. We're not bad people; we didn't make him sick.”

Why do mental illnesses continue to be stigmatized? For one thing, the term “mental illness” implies a distinction from “physical” illness, although the two are intimately coupled. For
example, schizophrenia is a progressive disease—the longer it is left untreated, the more brain cells a person actually loses. Some mental health advocates propose switching to less stigmatized terms, such as behavioral health or brain disorders.

In addition, we tend to say that people we do not like are “crazy” or “mental.” The media often portrays mentally ill individuals as comic. Some people also believe that if you have a mental illness, you must be dangerous and unpredictable. In fact, the opposite is generally true—mentally ill people are more likely to be the victims of crime because their odd action may provoke attack.

For someone with mental illness, the consequences of stigma can be devastating. Some people with mental illness don’t seek treatment for fear of being seen as less than other people. They believe that once family and friends find out about their illness, they’ll be scorned. They may try to hide their symptoms and not stick to treatment regimens.

Some people with mental illness become socially isolated. “With a physical illness, a person gets cards, balloons, phone calls, and offers of help. My son got none of that,” says Shimizu. “It isolates a person. You often lose friendships. People don’t know what to do to welcome someone with mental illness back into the fold.”

Indeed, statistics back up those feelings. In 2004, Mental Health Connection of Tarrant County and Community Solutions of Fort Worth, TX conducted a public attitudes survey on mental illness. Among the findings:

- More than 50 percent believe major depression might be caused by the way someone was raised, while more than one in five believe it is “God’s will.”
- More than 50 percent believe major depression might result from people “expecting too much from life,” and more than 40 percent believe it is the result of a lack of will power.
- 60 percent said an effective treatment for major depression is to “pull yourself together.”

**Parity: A Multi-level Issue**

Close behind stigma as a key reason that people do not seek treatment is the issue of cost. Many people cannot afford care and, in many cases, health care. According to a survey conducted by Mental Health Connection of Tarrant County and Community Solutions of Fort Worth, TX, 60 percent of people believe an effective treatment for mental illness is to “pull yourself together.”

**WHILE SOME PEOPLE voluntarily check themselves into a hospital for mental health care, many others are involuntarily committed. A person can be placed on an involuntary hold and be treated in a mental health facility if they are determined to be mentally ill and meet one of three criteria: imminent danger of self harm, imminent danger of harm to others, or grave disability. Law enforcement officers have the authority to place a person on involuntary hold as do physicians and mental health professionals who have been trained and certified by the Department of Mental Health. If a person is placed on an involuntary hold and committed to a Department of Mental Health designated facility, a physician has a minimum of 72 hours to evaluate the person and determine if more treatment is needed. “It can be very difficult and frustrating to try to help those with serious mental illness,” says Daniel Suzuki, MD, Medical Director at Las Encinas Hospital, which specializes in behavioral health care. “A person who has a schizophrenic illness, is actively delusional and is homeless may still not meet the criteria of grave disability for involuntary commitment if they can find shelter underneath a freeway overpass and panhandle for money.”

Even if a person is hospitalized, he or she cannot be forced to take medications. There is some recourse but it’s not pretty. If the treating physician believes that a patient who is refusing medications does not have the capacity to make such a decision, the physician can petition the Superior Court to request a hearing. Within two days from the time the doctor requests the capacity hearing, the patient will be contacted by an attorney from the Public Defender Office or, in some counties, a Patients’ Rights Advocate to prepare for the hearing. The patient is then scheduled for a hearing where a hearing officer or judge from the Superior Court will decide the issue of capacity to give or withhold consent to medical treatment. Unless there is an emergency, the patient cannot be medicated without giving consent until the hearing takes place. Then, if the court decides that the patient is not capable of giving informed consent, the doctor will be given authority to medicate the patient despite his or her objections.

Unfortunately, at times, people whose mental illnesses are acutely treated in the hospital and stabilized relapse due to noncompliance with outpatient treatment. In many cases outpatient resources for the chronically mentally ill without insurance are very limited. “Without mental health treatment centers and social support systems to encourage medication compliance and help with the psychosocial stressors that accompany mental illness, relapse rates can be high,” says Dr. Suzuki. “The good news is we have more effective psychotropic medications that are more tolerable and have fewer side effects. For example, we have new long-acting injectable antipsychotic medications that can help prevent rehospitalizations if we have systems to provide them to patients.”

For people who have insurance coverage and voluntarily seek inpatient treatment, options are greater, although not without challenges. In a typical insurance scheme of fail-first policy, patients must first fail to improve with outpatient treatment before they can go to the hospital for inpatient treatment. After acute stabilization, the patient then transitions to a partial hospitalization program where they receive treatment during the day and go home in the late afternoon.

“The mental health care delivery system in the U.S. is still very underfunded and fragmented,” says Dr. Suzuki. “I remain hopeful, however, that if physicians, hospitals, insurance companies and the public sector work together, then ultimately quality of care can succeed in a cost effective environment. And that is good for everyone, most importantly the patient.”
insurance coverage of treatment for mental illness is inadequate and far more limited than that for physical illnesses, such as diabetes or high blood pressure. Only 6.2 percent of current U.S. health care spending is devoted to the treatment of mental disorders. Although there is some legislation in place to help resolve the parity issue, it is often hard to enforce and new laws are difficult to get passed.

In March 2008, the U.S. House of Representatives passed the Mental Health Parity and Addiction Equity Act of 2008, a federal law that would require equal health insurance coverage for mental and physical illnesses, when policies offer coverage for both. The law came into effect on July 1, 2010 and, although a start, the law is not perfect. First, it applies only to group plans sponsored by employers of more than 50 people. State and local government employee plans may opt out of the federal parity law. Further, if a plan does not already cover mental health benefits, even in a limited fashion, the law would not pertain.

“Our number one concern is that despite the new Federal parity law, we have seen a reversal in insurance trends,” says Randall Hagar, Director of Government Affairs for the California Psychiatric Association. “Blue Shield and Blue Cross are being more restrictive. It’s cheaper for them if people are discouraged from psychotherapy and just get medications. So now they are beginning to use controls on outpatient psychotherapy—for example, requiring new approvals every couple of months. If you increase the hassle factor, people will give up.”

Prior to the Federal law, California passed Proposition 63, Mental Health Services Act, in 2004. This statute, which was authored by Selix and then-Assemblyman Darrell Steinberg, levied an additional 1 percent state tax on incomes of $1 million or greater to fund mental health service programs beginning in 2005. The program generated additional revenues of about $800 million in 2006-2007 alone. Much of the funding is provided to county mental health programs.

Other statutes, however, have not proven as easy to get through the legislative process. Assembly Bill 1600, Mental Health and Substance Abuse Parity, would expand mental health coverage requirements for certain health insurance policies issued, amended, or renewed on or after Jan. 1, 2011. Basically, the bill broadens the list of conditions to receive parity from a handful to all disorders included in the Diagnostic and Statistical Manual of Mental Disorders, which is published by the American Psychiatric Association. “The bill closes the loop on the effort started over 10 years ago to eliminate insurance discrimination against people with mental illness,” says Hagar.

Unfortunately, former Gov. Schwarzenegger vetoed the bill, claiming it would add costs to insurance premiums for individuals and would raise costs in employer supplied benefits. Hagar says those claims are unfounded. “Our data shows it’s really pennies per month for premiums,” he says. “The data comes from calculations of the California Health Benefits Review program at state universities.” And, he adds, “the argument about employers is specious. Plans give employers a price and then look at utilization data for the company. Employers who offer fewer mental health benefits have more costs in health services. We believe this bill will decrease employer costs.”

**The Bright Side**
Not everything is all doom and gloom. L.A. County has richer public mental health care than any other area in the United States. The county has established 60 wellness centers where people with mental health problems can get through the legislative process. Assembly Bill 1600, Mental Health and Substance Abuse Parity, would expand mental health coverage requirements for certain health insurance policies issued, amended, or renewed on or after Jan. 1, 2011. Basically, the bill broadens the list of conditions to receive parity from a handful to all disorders included in the Diagnostic and Statistical Manual of Mental Disorders, which is published by the American Psychiatric Association. “The bill closes the loop on the effort started over 10 years ago to eliminate insurance discrimination against people with mental illness,” says Hagar.

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illnesses can get medications, support, and psychotherapy. The centers all offer a strategy for social inclusion, aiming to get the community involved in making people with mental illness feel welcome.

Take, for example, the Northeast Wellness Center in Highland Park, which has become a model center for the county and has won state and regional awards for productivity and quality. Like all of the wellness centers, Northeast helps patients that are either new to the mental health system or who have just been released from a psychiatric hospital. “Our difference, however, is that we view the people who come here as ‘clients,’ not patients,” says Maria Aguilar, MD, a psychiatrist who works at Northeast. “And we look at them in terms of recovery rather than as ‘having an illness.’”

Not only does the center help their clients learn to manage—and eventually overcome—their symptoms, they encourage them to form meaningful relationships with others. As a result, the center has about 55 clients who volunteer for everything from clerical work to visiting other clients who are isolating themselves. Combined, the volunteers contribute about 250 hours each week to the center, which equates to six full-time staff positions.

For a resource-strapped public health entity that sort of dedication is huge. The clinicians can see more clients and the clients are getting better faster. “We couldn’t be as effective as we are without our volunteers,” says Dr. Aguilar. “Because of them we can treat more people. The volunteers are the hands and feet of the clinical staff.”

Also, the County’s crisis response team has begun taking a preventative stance to disasters, especially in regards to school violence. The education, legal and mental health systems have partnered up to respond to calls for help and provide interventions as needed. “In the past 18 months, the team has responded to over 250 potential problems, which ended up not being problems,” says Marvin Southard, Director of the Los Angeles County Department of Mental Health.

Tony Beliz, Deputy Director of the L.A. County Mental Health Emergency Outreach Bureau cites examples of positive work the partnership has achieved. “We had an adolescent female who was planning to kill her family members then go to school and kill some people she was upset with and then kill herself,” he says. Fortunately, a teacher saw her writings, which were acutely suicidal and also homicidal, and contacted Beliz’s office. “She had drawn up plans. Her family had no idea this was going on,” Beliz says. “We hospitalized her and gave her medications. When she was referred out, we got individual, family and group therapy for her so there was a safety net.”

Beliz is quick to point out that this is far from an isolated case. “You can’t imagine how many kids we are getting,” he says. “Some of them are just six or seven years old.”

In another case, an adolescent female chose one of the most notorious school shooters as her idol because their life stories were very similar. She researched the shooter on the Internet and proceeded to make plans for a shooting spree. Beliz says kids like her suffer from “isonection,” which combines the words “isolation” and “connection.” The children, he says, are often isolated emotionally and physically but are connected via the Internet.

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Still, it’s hard to recognize which children will suffer from mental illness. Beliz finds there is no typical profile for the children his team deals with. Many of them, he says, get good grades, have no history of disorderly conduct, have had no run-ins with the law and are of no particular ethnicity.

Suggestions Suggested
Beliz stresses that more must be done than simply asking children if they have suicidal thoughts. His team trains police officers to interview the person and their family, friends and teachers. Websites such as Twitter and Facebook can also reveal disturbed patterns of thought. He also believes that every school should have a threat management team who can discuss students of concern. “Teachers get students they are concerned about all the time and they don’t know what to do,” he says.

Southard adds that the L.A. County Department of Mental Health pays close attention to substance abuse or else it is a waste of their mental health dollars. “Evaluations and treatments for substance abuse are a regular part of the process in our adult centers,” he says. “And we are starting to implement that in our adolescent centers.”

Selix thinks that the medical home model might help. In his view, this integrated approach would allow the appropriate professional to deal with the patient immediately—a patient could avoid the issues of stigma, the care would be covered and easily approved and the patient would be spared the strain of finding a therapist. “Most physicians do not have a relationship with a mental health specialist,” he says. “A patient gets a list of therapists and an 800 number to call and then they are on their own. That’s a disincentive.”

Shimizu believes that physicians should stress that mental health is important, too, and offer to refer the patient to a therapist if they need to talk about something. “I would like to see us accept that people who are overcoming mental illness are worthy of attention and they are not contagious,” she says. “Mental illness is simply a part of human life—you’re still a person.”