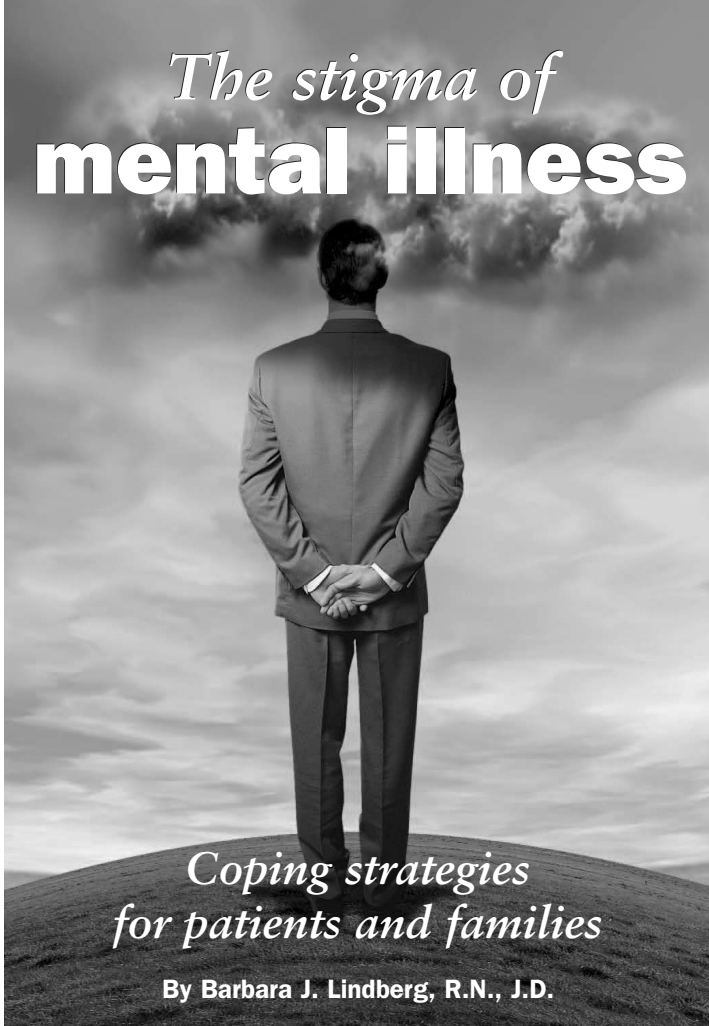


# MINNESOTA Health Care News

When 25-year-old John and his father arrived at the hospital, the only patient room reserved for psychiatric emergencies was full. They were escorted to a small, noisy lounge in the center of the emergency room. A security guard stood in the hallway just out of John's view. A woman whimpered in the next room. Machines rolled down the hall on noisy carts. There were monitors beeping and telephones ringing. John could no longer remember why he came here. The voices in his head were too loud. There were lots of them. Angry commands were followed by threats of frightening consequences. He was sure he heard his name being paged on a loud speaker.

A nurse came into the little lounge, but he was too distracted to hear what she was saying. John's father explained why they had come. She listened briefly and left. John's father wondered why they had to wait so long to be taken to the psychiatric unit. John's own doctor had approved the admission before they came to the hospital. A doctor finally came in and reached out to shake John's hand. John was afraid to be touched and did not respond. John thought the doctor didn't look like a doctor. The doctor asked the same questions as the nurse before had, and then also left. John



wondered why he was being punished by these people.

Four hours later, they were still waiting. The palms of John's hands were sweating. No one asked if he needed water. No one offered to take him to the restroom. No one offered him any medication. He worried about missing his two o'clock dose. John's father complained, but the shifts were changing and the nurse had already left. John's paranoid schizo-

phrenia was escalating out of control.

A nurse from the unit finally came. He approached John and said, "You must be Mike." John started to yell. He was lost in pain, anger, and confusion. More security guards were called, and his father was pushed aside. John feared he was going to be killed, and he started to cry.

Security threatened to restrain him. A voluntary admission ended in a terrifying

escort to the locked psychiatric unit.

## Stigma: What is it?

The stigma of mental illness is the primary reason for not seeking necessary mental health care. People like John who live with serious and persistent mental disease have a hard enough job just managing the symptoms and disabilities that result from a mental disorder. Their challenge is magnified when they must also endure prejudice and discrimination from a society that does not understand their illness. Their families suffer, too.

The first ever Surgeon General's report on mental health (U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*, 1999), states "stigmatization of people with mental disorders has persisted throughout history. It is manifested by bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance." Stigma leads many people to avoid interactions with people with mental disorders, depriving them of their dignity and interfering with their full participation in society.

## Behaviors that lead to stigma

Symptoms of mental illness become evident through certain behaviors. Unfortunately, these behaviors are judged by

others as character flaws instead of treatable neurobiological symptoms. Researchers refer to these behaviors as “signals” or red flags, and have identified four specific types: *psychotic behaviors*—when people who talk out loud to a person who isn’t really there; *social skill deficits*—when people prefer to be alone because of unreasonable discomfort around others; *physical appearance*—it becomes a signal when a person has poor personal hygiene or repeatedly wears the same dirty clothing; and (4) *labeling*—when people like John display red flag behaviors, it leads to labeling. Observers judge them and use names like “crazy” or “psycho,” when what the person needs is an advocate and some medical attention.

In the last 25 years, care for individuals with serious brain disorders has changed from an institutionalized setting to reintegration into the community. As a result, two important groups with a history of non-association—families and clinical workers—now must try to work together as partners.

Research by The National Alliance on Mental Illness indicates that 65 percent of patients discharged from a hospital either live with or receive primary assistance and support from a family member. Historically, families were asked to disengage from the care of their loved one; now they are expected to be the primary caregiver. In this role, they are desperately asking for compassion, understanding, and teamwork from mental health professionals so they can help their loved ones achieve the highest possible

## Tips for de-escalating a crisis

- **Offer support. Do not deny their psychotic thinking.**
- **Speak and act slowly and clearly using simple sentences.**
- **Don’t try to reason with a person in psychosis.**
- **Give them space and avoid direct eye contact.**
- **Keep stimulation low.**
- **Emergency personnel and families need to avoid the tendency to act assertively. Loud voices and quick movements may aggravate the crisis.**

quality of life.

Many health care providers find themselves in the same situation. They are not adequately prepared to treat serious and persistent mental disorders. If a patient does not seem to get better or follow the treatment plan, the clinician may succumb to patterns of stereotyping and stigma.

### Stop the stigma

Individuals and families who are caregivers for a person with a mental disorder can advocate for better treatment in clinical settings. The first step is to seek out and work with clinicians who offer hope and direction. Partnerships among patients, families, and caregivers promote patients’ personal growth and hope for better outcomes.

In addition, maintaining adequate knowledge of neurobiological brain disorders is a key factor in the fight against the stereotyping and stigma. Families and caregivers must learn about their loved one’s illness by reading all of the information they can find. Education helps to reduce family anxiety and confusion.

Spending time with others who are living and managing similar situations is important. Family members learn that they are not alone, and their struggle is not unique or shameful. It is OK to be angry and frustrated, but families

must also understand the reality of a long-lasting disability. Expectations of their loved one must be appropriate to their level of disability. Support systems, including extended family and friends, help to promote patience and hope during the recovery process.

In addition, families must do the following:

- *Learn how to help manage the illness in a positive manner*, by being involved in hospital discharge planning; offering day-to-day information to clinicians on the progress or changes in their loved one’s illness and expect the same information from the clinician; staying informed about changes in medications or therapy in order to monitor their family member’s compliance; and viewing themselves as a partner in the clinical team, not an adversary.

- *Understand symptoms, medications, and side effects.* Managing mental illness is a 24-hour job. Know your family member’s symptoms, and accept them as part of the illness. Symptoms of mental illness are not a reflection of a person’s character. People should not be misjudged or punished for behaviors they cannot control. Medications treat symptoms, but may also create problematic side effects. Families must be aware of signs to watch for. Keeping clinicians informed of side

effects will improve medication management for their family member.

- *Learn how to recognize and manage a crisis.* Most families are familiar with how their family member thinks or acts when in a psychiatric crisis. Emergency personnel must also be aware of these symptoms. (See the sidebar for tips for de-escalating a crisis.)

Families are a valuable asset to the clinical team as they attempt to manage their loved one’s mental illness. The National Alliance on Mental Illness (NAMI) is one of the many mental health organizations in Minnesota that offers education and support to families looking for help. NAMI is a grassroots organization formed by families living with mental illness. In addition to area support groups, NAMI offers educational programs such as Family-to-Family, a 12-week course for families to learn the skills required to help their loved one; and Hope for Recovery, a one-day course about brain biology, treatments, and recovery.

As described by the Surgeon General, stigma is a burden undeserved by those who bear its pain. We all need to join in the fight against stigma, especially for those who courageously live with a serious and persistent mental illness. ■

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