

Review

Lonely in a crowd

— The effect of mental illness on sufferers and their families —

Smita N. DESHPANDE

*M. D., D. P. M. Senior Psychiatrist
Ram Manohar Lohia Hospital, New Delhi*

Mental illness affects not only the unfortunate sufferers themselves, but the family: parents, children, spouse and friends too. This stigma operates at multiple levels (community, societal, familial, individual) to dehumanize and delegitimize individuals with mental disorders (Hinshaw and Cicchetti, 2000). Mentally ill people are regarded as unable to look after themselves or perform any productive work.

Mental illness may be regarded as a curse due to moral weakness ("bad deeds"), or something shameful that runs in families (bad blood) (Agarwal, 1998). The belief that it is due to the effect of evil forces also exists, but this belief is gradually being replaced in educated societies with half baked knowledge about the "psychological causes" and "ways to combat mental illness through strength of mind" models of mental illness. The mentally ill person is supposed to get over the illness by being strong, by battling the symptoms, and carrying on as if nothing has happened.

No one can "see" mental illness the way a fever can be felt or a broken limb seen. Yet the moment a sufferer speaks, or behaves in an atypical way, the observer knows something is wrong and more often than not, reacts negatively. The reaction may take the form of blaming everything the sufferer does on his/her illness. It is as if the person is lost and only the illness remains.

The stigma of mental illness seems to be a fear of the unknown and a symbolic fear of one's own vulnerability. The observer seems to feel that "there but for the grace of God go I". But unfortunately, a rejecting or fearful reaction is more common than a positive sympathetic one.

Some Examples

Here are a few case studies of the effect of this rejection and fear, also called "stigma" and how it affects sufferers and carers. Identities have been disguised.

Subhadra was in her senior year in school when she fell ill with schizophrenia. She used to believe that her father poisoned her curry and then molested her through this poisoned curry. Her parents sought the best treatment for her, but stopped her schooling, possibly due to her odd beliefs and their embarrassment about these beliefs. Now a decade later this beautiful girl remains uneducated, untrained and dependent.

People are conversely also ready to label anyone as mentally ill at every sign of aberrant behaviour. One person who was aloofly non-cooperative (and non-productive) in office was sent to the psychiatry department to be declared medically unfit for service because one day he lost his temper and threw some books around. There had never been any prior symptoms of mental illness. Thus men suffer from discrimination and stigma just as much as women, in their case the teasing and shunning often begin in the workplace.

Sometimes families themselves victimize sufferers because of their wrong beliefs. One woman, a schizophrenia sufferer, was not allowed to touch anything in her house because of the family's mistaken belief that the disease was infectious!

Marriage, Mental Illness and The Burden

In India, the chief duty of the parents of grown-up children is to get them married. Parents go to any extent to hide mental illness in

their children, rightly believing that revealing this fact will jeopardize the marriage. Yet with changing social mores, such unfortunate marriages end in divorce, if not something worse.

After getting married to another doctor after the onset of her illness a lady doctor almost immediately attempted suicide possibly due to the stress of adjusting to her husband's joint family. Her mother had always refused to believe that her brilliant daughter had been ill in any way but the suicide attempt precipitated matters and psychiatric treatment was begun. However possibly fearing shame and stigma, every time this lady doctor visited her, her mother would ask her to stop medicines and "snap out of it". Her unreal voices, her fears were all imaginary. The lady doctor would obey. Finally the stress proved too much and she jumped from the eighth floor of her building.

Conversely, sometimes the lack of insight a sufferer has into mental illness can take a terrible toll on carers. Take for instance an old gentleman whose wife suffered from bipolar disease with the severe mood swings characteristic of this disease. During her manic phases she would remain sleepless, often wandering outside the house at night. The husband was so scared of something bad happening to his wife that he too would not sleep in spite of the various physical illnesses he suffered from. Finally, he had a heart attack and the wife and young son were left to cope on their own.

Very often the greatest hidden burden falls on the children. They are racked by guilt at the illness of their parent, and wonder if their own children will fall ill due to such illnesses running in families. Sometimes these children refuse to marry or subsequently refuse to bear children for fear of abnormalities in their progeny.

Some friends suffer too. I know of a lady who looks after her friend with bipolar disorder and treats her like a normal capable and lovable person. Yet the moment she falls ill, this patient is often the first to blame this friend/caretaker and find faults with her. I am glad to say that in spite of these ups and downs the friendship has endured over several years and several episodes of illness.

Unfortunately, the sufferers may themselves internalize these negative perceptions about themselves. In such cases the negative

stereotyping becomes a self fulfilling prophecy. Yet as the movie "The Beautiful Mind" illustrates, mental illness is no bar to creativity. Several studies from India and other developing countries have shown that where expectations from such sufferers about working and earning their own living are high, outcome can be surprisingly good and a majority of sufferers remain in gainful employment.

FEAR OF VIOLENCE

Mentally ill persons are often viewed with fear because people feel they will become violent at no provocation. This is simply not true. While people with schizophrenia are significantly more likely to be violent than other members of the general population, the proportion of societal violence attributable to schizophrenia is small (Walsh, Buchanan and Fahy, 2002), and the proportion of violent crime in society attributable to schizophrenia consistently falls below 10%. Less focus on the relative risk and more on the absolute risk of violence posed to society by people with schizophrenia would serve to reduce the associated stigma.

Just like all crimes, the majority of violent crimes are committed by "normal" people, whether violent or otherwise. Of course if a mentally ill person feels s/he is being unreasonably labeled or restrained, s/he is likely to protest sometimes with violence. The rationale for shutting up mentally ill people in mental asylums used to be the fear of their violence. With early and adequate treatment, violence among the mentally ill has almost disappeared today.

COMBATING STIGMA

Not only serious mental disorders, even relatively less disabling ones such as headaches and anxiety are also stigmatized. Women fall ill with depression more often, yet they are stigmatized as pretenders or deliberately assuming symptoms. Adopting a medical model of illness and an increased emphasis on biological causes of mental illness may help combat stigma (Schreiber and Hartrick, 2002). From this perspective, the current genetics revolution can be seen as a source of hope. Biological attributions could conversely increase stigma, for example by making the ill person seem 'defective' or 'physically distinct' — 'almost a

different species' (Phelan 2002).

How to combat stigma? With modern scientific treatment the most severely and chronically mentally ill people can recover and go back to work even if partially disabled. The more a disorder is hidden, the more it is feared and stigmatized. Both sufferers and carers need to come out in the open and declare their illness, discuss its symptoms and find new remedies. An example is that of mentally retarded persons. In India the parents fought for the right of their intellectually handicapped children to have special schools, disability insurance and reservations in jobs. Many parents' organizations began schools for these special children. Ultimately these activities reduced stigma and guilt and helped achieve social acceptability for these children.

A similar mass movement by all people involved with mental illness is needed. Such a movement has received a boost in India with the formation of a number of family and sufferers groups working together (at present only for the rights of the mentally ill). It is hoped that this movement will grow to encompass rehabilitation, treatment, care and after care too. It is hoped that Disabilities Act of the Government of India will also help bring out the illness in the open. Under this Act specified disabilities are certifiable and certain concessions and job reservations are provided to such disabled people.

Since Independence, partly due to shortage of resources and partly due to genuine concern, treatment of mental disorders has moved away from the mental hospitals into the general hospitals and in some places even into the community in India. Regular psychiatric camps are held to identify and help sufferers and make them aware of treatment modalities available. This helps combat stigma by emphasizing that these are illnesses like any other medical illness. Mental illnesses are treatable. This knowledge encourages early entry to care, improves outcomes and lessens the stigma and discrimination related to mental illness (Herrman, 2001). Moreover in spite of having to live with sorrow, anguish,

constant worry, guilt and shame, caring for a mentally ill relative can nevertheless be enriching and satisfying (Yanos, Rosenfield and Horwitz 2001). As mental health personnel learn to depend on caretakers to improve the sufferer's quality of life, this is an aspect all should be aware of.

References

- Aggarwal A. K. (1998) Forgotten Millions. *Indian Journal of Psychiatry*, 40 : 103-119.
- Chung K. F., Chen E. Y., Liu C. S. (2001) University students' attitudes towards mental patients and psychiatric treatment. *International Journal of Social Psychiatry*, Summer, 47 : 63-72.
- Corrigan P. W., Green A., Lundin R., Kubiak M. A., Penn D. L. (2001) Familiarity with and social distance from people who have serious mental illness. *Psychiatr Serv*, Jul, 52 : 953-8.
- Govt. of India Gazette: Persons with Disabilities (Equal opportunities, protection rights and full participation) Act, 1995.
- Herrman H. (2001) The need for mental health promotion. *Aust. N Z J Psychiatry*, Dec, 35 : 709-15.
- Hinshaw S. P., Cicchetti D. (2000) Stigma and mental disorder: conceptions of illness, public attitudes, personal disclosure, and social policy. *Dev. Psychopathology*, Autumn, 12 : 555-98.
- Holland J. C. (2002) History of psycho-oncology: overcoming attitudinal and conceptual barriers. *Psychosomatic Medicines*, Mar-Apr, 64 : 206-21.
- Pejlert A. (2001) Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health Soc Care Community*, Jul, 9 : 194-204.
- Phelan J. C. (2002) Genetic bases of mental illness - a cure for stigma? *Trends Neurosciences* Aug, 25 : 430-1.
- Rains J. C., Penzien D. B., Martin V. T. (2002) Migraine and women's health. *Journal of Am Med Womens Assoc*, Spring, 57 : 73-8.
- Schreiber R., Hartrick G. (2002) Keeping it together: how women use the biomedical explanatory model to manage the stigma of depression. *Journal of Nerv Ment Dis*, Feb, 190 : 108-14.
- Veltman A., Cameron J., Stewart D. E. (2002) The experience of providing care to relatives with chronic mental illness. *Journal of Nerv Ment Dis*, Feb, 190 : 108-14.
- Walsh E., Buchanan A., Fahy T. (2002) Violence and schizophrenia: examining the evidence. *British Journal of Psychiatry*, Jun, 180 : 490-5.
- Yanos P. T., Rosenfield S., Horwitz A. V. (2001) Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal*, Oct, 37 : 405-19.