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SCHIZOPHRENIA:

Youth's Greatest Disabler

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Message from the Regional Director

Populations of Member Countries of the World Health Organization's South-East Asia Region have suffered for ages from many communicable diseases. While some of these have been successfully controlled, others continue as serious public health problems. However, recently, it has become increasingly clear that noncommunicable diseases, including mental and neurological disorders, are important causes of suffering and death in the Region. An estimated 400 million people worldwide suffer from mental and neurological disorders or from psychosocial problems such as those related to alcohol and drug abuse. Our Region accounts for a substantial proportion of such people. Thus, the Region faces the double burden of diseases – both communicable and noncommunicable. Moreover, with the population increasing in number and age, Member Countries will be burdened with an ever-growing number of patients with mental and neurological disorders.

As Dr Gro Harlem Brundtland, the Director-General of the World Health Organization says, "Many of them suffer silently, and beyond the suffering and beyond the absence of care lie the frontiers of stigma, shame, exclusion and, more often than we care to know, death".

While stigma and discrimination continue to be the biggest obstacles facing the mentally ill, inexpensive drugs are not reaching many people with mental and neurological illnesses. Although successful methods of involving the family and the community to help in recovery and reduce suffering and accompanying disabilities have been identified, these are yet to be used extensively. Thus, many population groups still remain deprived of the benefits of advancement in medical sciences. Dr Brundtland has said, "By accident or design, we are all responsible for this situation today."

The World Health Organization recently developed a new global policy and strategy for work in the area of mental health. Launched by the Director-General in Beijing in November 1999, the policy emphasizes three priority areas of work: (1) Advocacy to raise the profile of mental health and fight discrimination; (2) Policy to integrate mental health into the general health sector, and (3) Effective interventions for treatment and prevention and their dissemination. The South-East Asia Regional Office of the World Health Organization is committed to promoting this policy.

Mental health care, unlike many other areas of health, does not generally demand costly technology. Rather, it requires the sensitive deployment of personnel who have been properly trained in the use of relatively inexpensive drugs and psychological support skills on an outpatient basis. What is needed, above all, is for all concerned to work closely to address the multi-faceted challenges of mental health.

Dr Uton Muchtar Rafei
Regional Director
World Health Organization
Regional Office for South-East Asia

Preface

Dr R.D. Laing, a British psychiatrist wrote: “Schizophrenia cannot be understood without understanding despair.” This was written in the early twentieth century, but still remains true for the majority of patients suffering from schizophrenia today.

While one-half of the world is privileged to have the entire gamut of intervention strategies, including newer medications, and benefits from research, the other half, primarily comprising the developing countries, does not have access even to basic mental health facilities or medication.

Dr Laing’s statement appears to be true even today in the context of lack of understanding of schizophrenia and other mental disorders, the stigma attached to it, and the high cost and non-availability of effective medicines. It is time, therefore, to take urgent corrective measures.

It is essential that policy-makers address this issue with a sense of urgency. Considering that conditions affecting the mind such as depression and schizophrenia account for the major portion of disability, we cannot be complacent.

The WHO Regional Office for South-East Asia is committed to help Member Countries to develop community-based projects and programmes to address issues related to schizophrenia and other mental disorders.

This document, prepared by a panel of experts from the Region, provides valuable information for the lay public and policy-makers regarding the multi-faceted aspects of “youth’s greatest disabler” and what can be done to relieve this disability.

Dr Vijay Chandra
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Introduction

Schizophrenia is a major mental disorder, with an ubiquitous distribution all over the world. It is also a leading public health problem which entails enormous personal and economic cost as it affects nearly one per cent of the world's population. It does not respect any boundaries and cuts across gender, socioeconomic groups, educational status, geographical location, caste and community. It normally occurs during the most productive ages - between 15 and 35 years - and can affect both children and the elderly.

If treated partially or left untreated, schizophrenia can cause significant and long-lasting impairment and disabilities, encompassing all aspects of human functioning. It makes heavy demands on hospital care, and may require prolonged medical care, rehabilitation and support services. The social costs and burden on the family can be enormous.

More recent research has focused on the biological aspects of schizophrenia and includes genetic studies, radiological investigations as well as biochemical and neuropathological studies of the brain. The body of knowledge gathered over the years has ultimately led researchers to term schizophrenia as a “disorder of the brain”, although its exact etiology is yet to be determined.

The other benefits of research have been the discovery of new antipsychotic medications which are more effective against certain symptoms of schizophrenia, as well as a more comprehensive approach to treatment and rehabilitation. Also, the role of the patients themselves and their families is increasingly being recognized as a critical element of any intervention.



Yogeeta

Historical background

“There is a form of insanity that occurs in young persons ... the attack that is almost imperceptible ... a degree of apparent thoughtfulness and inactivity coupled with a diminution of ordinary curiosity ... they do not bear the same affection towards their relations ... the tears that trickle down one moment are as unmeaning as the loud laugh that succeeds them ... they become negligent in their dress and inattentive to personal cleanliness... I have painfully witnessed this hopeless and degrading change many a time.” Haslam (1809)

Historical writings are replete with references to descriptions of the mentally unsound. The term *unmada* (denoting insanity) first appeared in the passages of the Atharvaveda, believed to be written around 1500 BC. By the period of the Samhitas, a thousand years later, clinical sub-varieties of *unmada* had been documented.

In Ayurveda, a traditional Indian system of medicine, conditions such as *vatanmada*, *pithanmada* and *kaphonmada*, which correspond to psychosis and depressive states, have been described. Bangla literature also describes schizophrenic patients as *pagal*, *unmad*, *mathakarap* (implying insanity and complete disorganization of the personality), *unmana* and *bekhali* (connoting social withdrawal and apathy).

Although the disease was described in a variety of ways, the methods of treatment recommended were the same for all types of *unmada*. The objective of the treatment was to restore the patient's equilibrium. Medications, therapeutic procedures and non-medical treatment methods, such as psychotherapy (*satwavajaya*), counselling, recreational therapy and prayers, were all used in different combinations.

The ancient Greeks and Romans were aware of mental health issues. This is evident from the writings of Aretaeus (AD 1) and Soranus (AD 100), who described the ‘insane’ as people who were free to wander about, availing themselves of the healing properties of facilities such as medicinal baths and temples along with the physically ill. It appears that a humanistic attitude to mental illness prevailed during that period. Zillboorg (1941) has recorded that Byzantium (Rome) had a ‘moratorium’ to house the mentally ill.

The treatment of the mentally ill remained crude and even bizarre for a number of years. The patients were subjected to most inhuman methods such as trephining of the skull to “dispel the poisonous gases”, surgical removal of various parts of the body to “remove the poison”, and induction of coma using different kinds of medications.

The first special establishments for the mentally ill were set up by the Arabs in the twelfth century BC. In keeping with Islamic teachings, the *Dal Almeraphtan* or the House of Grace was set up in Baghdad in 1173 BC. Its residents were allowed to wander freely in the gardens and their treatment included drugs and music.

In Thailand, the first psychiatric hospital was established in 1889. As most of the patients were psychotic and because their numbers kept growing rapidly, it came to be called a psychotic hospital. The patients in the hospital were injured, chained, restrained, soaked with holy water and so on, in keeping with the myth that these methods could free them from evil spirits and spells. Initially, the treatment consisted of traditional Thai medicines, i.e. herbal medicines; later, modern medicines began to be used. Modern treatment started receiving importance about 90 years ago. Some diagnostic terms in modern psychiatry (including schizophrenia) have been in use in Thailand for nearly 70 years.

The empirical approach to this disorder had its beginnings in the eighteenth century. As pointed out by the historian Foucault (1967) and the sociologist Scull (1979), the severely mentally ill were separated from other 'deviants' in society during this period. The focus gradually shifted, with the mentally ill being regarded as socially marginalized people, deserving humane modes of treatment and sympathy, rather than being seen as incomprehensible and unapproachable.

Two names that are associated with the modern history of schizophrenia are Emil Kraepelin and Eugene Bleuler.

By merely observing his patients closely and intensively, Kraepelin gave order and structure to general impressions, giving his observations a scientific status. He found that this disorder has its beginnings in early life, takes an essentially downhill course, culminating in an intellectually

The treatment remained crude and even bizarre for a number of years and the patients were often subjected to most inhuman methods



Yogeeta

deteriorated state. He used the term, “dementia praecox” for this condition.

In 1911, Eugene Bleuler found that not all patients failed to improve. On the basis of his observation of patients’ reactions to personal and social influences, he preferred to call the disorder ‘schizophrenia’, or rather, a group of “schizophrenic psychoses”. The word schizophrenia means a splitting in mental functions (schism = split, phrenos = mind) but not a split personality. His most important contribution was the postulation of a basic mental disturbance causing schizophrenia.

Other scientists who have contributed to the advancement of our understanding of schizophrenia are Schneider, who described first-rank symptoms; Karl Jaspers, who worked on the psychopathology aspects; and Philip Pinel, who introduced humane treatment for the mentally ill.

Theories about schizophrenia which are not true

Various theories have been put forward to explain the genesis of schizophrenia and these have distorted understanding of the illness. Virtually all the theories, ranging from those implicating dysfunctional families to those implicating dysfunctional brains, include a caveat that schizophrenia is not a unitary disease but a spectrum of disorders, and that its occurrence may be explained by more than one factor.

Family communication and interaction theory

For a long time, the patient’s mother was seen as the object of blame, being described as ‘schizophrenogenic’. Even textbooks of psychiatry put forward the view that a majority of cases of schizophrenia were caused by mothers who were “overanxious, obsessive, domineering and had a warped sex life”. Contradictory communication in different sections of society was added to this list, which served to induce an unnecessary sense of guilt among patients’ mothers and families.

Viral theory

In the early 1900s, when the microbiological agent, spirochete causing syphilis was discovered, a lot of interest was generated in the possibility that schizophrenia had a viral origin. Theories about schizophrenia centering around viruses attacking the brain, the few similarities between encephalitis (brain infection) and schizophrenia, and the role of slow viral infection (which would account for the long latency period before the clinical manifestations of the illness), have all been postulated. None of these, however, have stood the test of time, and have been shown to be false.

What, however, needs to be understood is that the major focus of any intervention should address the human needs and disabilities caused by the disorder, as well as the burden on the family and the cost to society.

Stress theories

In the early twentieth century, stress was commonly believed to cause schizophrenia and also to contribute to relapse. Problems at the interpersonal level, at work and in the family were all held to be responsible, especially by the family and the community. Later, researchers invoked the stress-diathesis model, which postulated that some people are genetically more vulnerable to breakdown in the face of stress. While stress can certainly complicate the life of schizophrenics and their families, its causal role in schizophrenia is still unclear.

Other theories

Theories implicating nutritional deficiencies, alterations in the chemistry of the brain, and changes in the immune system rendering the individual more susceptible to schizophrenia have been hypothesized, but more research is needed.

All kinds of theories - biological, physiological, psychological, psychodynamic, behavioural and environmental - have been postulated for the causation of this disorder. While schizophrenia is best described as a 'bio-psychosocial' disorder, it is anticipated that a clear biological model will soon emerge.

Myths and misconceptions about schizophrenia

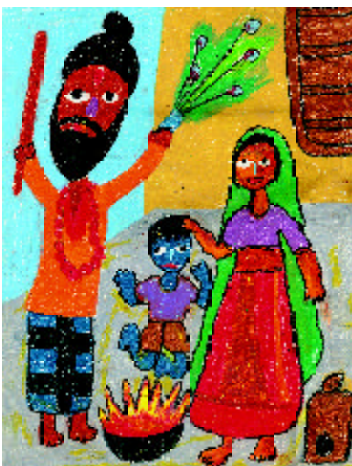
What do people understand by schizophrenia?

The understanding of a subject depends on its complexity. This is particularly true of schizophrenia, which has remained an enigma over several centuries because its exact causes are still not clear, even after decades of intensive research. It is an enigma because it has a biological basis, in the form of disturbances in the brain structure and functioning, but its manifestations are largely behavioural, with enormous social ramifications. The issue of stigma and social ostracism makes it even more difficult to provide effective care to those suffering from schizophrenia.

Various notions regarding many health problems, be it physical or mental, abound in the public mind. These are based on concepts passed on from generation to generation, the experience of individual families, and the views expressed in the media. Cultural, social and educational factors play a predominant role in shaping these views. The absence of health centres for the treatment of various disorders in a large majority of rural areas has only served to further entrench these beliefs. Schizophrenia is no exception to this rule. As its etiology is still unclear and its manifestations often bizarre, its causation, symptoms, treatment and potential for cure/improvement are naturally apt to be interpreted in a myriad ways.

The term “explanatory model” is used to refer to ways in which communities identify, assign meaning to and handle mental disorders. There is a distinct difference between the models advocated in the developed and developing countries, with the former being principally medical/biological, and the latter being non-scientific (magical/religious). There are, however, two important exceptions to this. First, not all countries in either hemisphere are culturally identical, but they do share attitudes and perceptions regarding mental disorders. The second is that the beliefs in urban regions of developing countries more closely resemble the beliefs in developed countries.

Populations in the countries of the South-East Asia Region, particularly rural communities, continue to perpetuate numerous myths about schizophrenia.



Prajapati Shikha Jayeshbhai

Myth:

Schizophrenia is a curse.

Fact:

Schizophrenia is a medical illness. It is not a curse. It is not a wish of the Gods and it is not black magic that is being practised to settle family rivalry. These misconceptions have been perpetuated for generations and are more common in rural areas. Every effort must be made to dispel these beliefs by educating families and communities.

Myth:

Schizophrenia must be treated by sorcerers and faith-healers.

Fact:

Schizophrenia must be treated by qualified medical professionals with allopathic medications. Rituals performed by sorcerers and faith healers have no role in the treatment of schizophrenia. Many of these rituals can be harmful and can even be a risk to the life of a patient.

Myth:

Schizophrenia is penance for sins in a previous life, so why go to a doctor?

Fact:

This sense of fatalism deprives a patient of effective treatment. Patients, families and communities need to be aware that this illness has nothing to do with the philosophy of rebirth and sins of previous lives.

Myth:

Schizophrenia must be treated in places of worship.

Fact:

Practice of religion can have a calming influence on patients and families and religious leaders can often be very effective counsellors. However, neither religion nor religious places can treat this illness. Fortunately, most enlightened religious leaders will advise patients to seek medical treatment.

Myth:

Schizophrenia is split personality, like Dr Jekyll and Mr Hyde.

Schizophrenia must be treated by qualified medical professionals with allopathic medications. Rituals performed by sorcerers and faith healers have no role in the treatment of schizophrenia. Many of these rituals can be harmful and can even be a risk to the life of a patient.

Fact:

The Dr Jekyll and Mr Hyde story is fiction. Unfortunately, however, it is very popular and schizophrenia is equated with split personality. This is not true.

Myth:

Patients with schizophrenia are dangerous and should be confined to the house, hospitals or jails.

Fact:

Most patients with schizophrenia prefer to be left alone and do not harm others. However, some patients, particularly those with a history of substance abuse or alcohol abuse, can become violent. Such episodes often occur when they are hearing voices or imagining threats to them. Patients should be handled in a calm reassuring manner without fear.

Myth:

Patients with schizophrenia are useless and unproductive and a burden on the family.

Fact:

With proper medical treatment, rehabilitation and supportive environment, many patients can perform simple tasks, particularly in a sheltered environment. Although they require training, the effort is rewarding for the patient, the family and the community.

Myth:

This disease is completely incurable.

Fact:

It is true that prolonged treatment may be required for schizophrenia but with proper management, the patient can lead a fairly comfortable life within his family and community.

Schizophrenia is a mental disorder interfering with a person's ability to recognize what is real, manage his or her emotions, think clearly, make judgements and communicate.

People with schizophrenia usually suffer strange symptoms, such as hearing imaginary voices, and believing that these voices are controlling their thoughts and actions. They may believe that people are plotting to harm them. They become frightened and withdrawn. Their speech and behaviour become disorganized.

The onset of schizophrenia is generally gradual, and rarely sudden or dramatic. Certain symptoms can develop slowly, in an almost imperceptible fashion, while other symptoms develop more rapidly and are very easy to recognize.

Scientists have classified the symptoms of schizophrenia as positive and negative. 'Positive' does not imply that the symptoms are 'good' for the patient, but that they are easily noticeable, more disruptive to the family, more distressing to the patient and make the patient more responsive to medicines. Some of the positive symptoms are hallucinations, delusions and thought disorders.

The negative symptoms are not easily discernible and are not very disruptive socially, but can be more disabling than the positive symptoms. Patients with these symptoms are generally less responsive to medicines. Reduced motivation and drive, difficulty in experiencing pleasure, lack of emotions and lack of energy are some of the common negative symptoms. The patient displaying these symptoms is often taken to be deliberately lazy or not making an effort, and the family may turn hostile towards him/her on account of these symptoms.

Behavioural changes

A common manifestation is behavioural change. Often, this is more easily recognized by the family members, who then take the patient to a doctor. Behavioural change could take different forms, such as social withdrawal, isolation, restlessness, irritability, aggressiveness and antisocial behaviour. These result in an impairment of day-to-day

What is schizophrenia?

Description of a person suffering from paranoid schizophrenia by a neighbour

"He is a young man of 25. He used to be very good looking, but now he is dirty, does not bathe or shave, uses vulgar language, keeps shouting at people and it appears he is talking to himself. He is worse on full moon days... People say he has gone mad, because an evil spell has been cast over him. The village people say it is to punish his family. He has been like this for 5 to 6 years. In the beginning, he was taken to a magician, then to a faith healer who lives far away in the mountains, but he did not improve. This year, he was taken to hospital and now he is much better."

Anonymous

My true story...

“The visions are extremely vivid. Paving stones transform into demonic faces, shattering in front of my petrified eyes. When I am in contact with people, they can become grotesquely deformed..... Buildings and rooms spin and weave and their walls close in as I look on, paralysed by fear... The voices either ramble in alien tongues or scream orders to carry out violent acts. They also persecute me by way of unwavering commentary and ridicule to deceive, derange, and force me into a world of crippling paranoia.”

- Robert Bayley, a schizophrenia sufferer, in Schizophrenia Bulletin, No. 4, 1996, published by the National Institute of Mental Health (NIMH), USA

Source:

<http://my.webmd.com/content/article/1680.51904> dated 12 Jan 2001

functioning - a drop in school attendance and performance, increasing unproductivity, difficulties in interpersonal relationships, neglect of household activities and preoccupation in a personal world are the common manifestations seen in clinical practice.

Delusions

Delusions are patients' fixed belief in something that is obviously untrue. They may believe that they are being persecuted, that people are conspiring against them at work or at home; they may suspect their spouse of infidelity and may take to watching them constantly; they may believe that their thoughts are being controlled by some external force, e.g. that a radio receiver is planted in their head. These beliefs will not be shaken by attempts to reason with them.

Hallucinations

Hallucinations are imaginary voices which the patients hear and respond to. They are seen apparently talking to themselves in a disjointed way, often laughing, gesticulating or smiling. These voices can be distressing and can sometimes control the patients. Often, the patients see frightening figures and their fear may make it difficult for others to control them. They could even be driven to suicide.

Thought disturbances

Schizophrenia is often characterized by disturbances in thinking - this may be reflected in incoherent and irrelevant speech. The patients may also report that their thoughts are muddled, are withdrawn by somebody else or that other people get to know what they are thinking. The patients may also believe that thoughts are inserted into their mind.

Loss of interest and social withdrawal

The persons start losing interest in their work, studies, family and friends. They are irritable, look vacant when questioned, stop going to work, and spend time wandering aimlessly or doing nothing, looking preoccupied

or lost in thought. This is usually accompanied by a sharp fall in academic or work performance, disturbed sleep patterns and loss of appetite. The individuals also begin withdrawing into themselves, shunning company and social interaction of any sort.

Disinterest in personal hygiene

In the later stages, the patients refuse to bathe or keep themselves clean, and lose interest in their physical appearance and that of their surroundings.

Inability to express emotion

Patients become emotionally 'blunted' - they are unable to express appropriate emotion and do not appear to be in touch with reality outside of themselves. Many complain that they neither feel sad nor happy.

Lack of attention and concentration

This is very often a symptom of schizophrenia and may be reported either by the patients or any of their family members. They could have difficulty in performing daily activities such as reading the newspaper or watching television. Because of this, they leave tasks half done or undone. This is a frequent problem with patients who return to work.

Lack of insight

Very few schizophrenics know or admit that they have a problem. They often deny any illness or difficulty, sometimes blame those who take them to doctors, or attribute everything to a physical illness. This can delay or hinder the treatment process.

It is not often that all the symptoms described appear in any one individual or at the same point in time.

Prodromal symptoms

Apart from the well-established symptoms described so far, there are what are called prodromal symptoms. The term 'prodrome' generally signifies the prepsychotic period

Most common prodromal features before first episode of psychosis (in descending order of frequency)

- Reduced concentration, attention
- Reduced drive and motivation
- Depressed mood
- Sleep disturbance
- Anxiety
- Social withdrawal
- Suspiciousness
- Deterioration in role functioning
- Irritability

Source:

Yung AR, McGorry PD. The prodromal phase of first-episode psychosis: past and current conceptualizations. *Schizophrenia Bulletin* 1996; 22(2): 353-70

Mental disturbances resembling psychosis can occur in other conditions such as:

- Childbirth
- Head injury
- Ingestion of toxins, including street drugs
- Temporal lobe epilepsy
- Mental retardation
- Encephalitis
- Intake of some prescription drugs, including certain antimalarials

before the onset of the illness, or that preceding an episode of relapse. Initial prodrome is defined as the period of time from the first change in an individual until the development of clear psychotic symptoms.

Very often, a patient has similar prodromal symptoms before each episode of relapse. It is important for both the patients and their family members to be aware of this in order to facilitate early intervention.

Co-morbidity with schizophrenia

Persons with schizophrenia also suffer from a greater degree of co-morbidity with associated conditions like alcohol abuse, abuse of stimulant drugs, caffeine, tobacco and others. An increased risk of HIV/AIDS, suicides and other mental disorders are also associated with schizophrenia. The course and outcome from schizophrenia also worsens over a period of time due to the presence of co-morbid conditions.

What is not schizophrenia?

Another psychiatric disorder is manic-depressive psychosis. This is characterized mainly by episodes of elevated mood and increased activity (called hypomania or mania in medical terms) which could alternate with spells of depression. Some people can have repeated episodes of either hypomania or depression alone. It is sometimes difficult to clinically distinguish this from schizophrenia.

Schizophrenia is not a splitting of the personality into different parts, as portrayed in Dr Jekyll and Mr Hyde or The Three Faces of Eve. Nevertheless, the idea that schizophrenia means split personality is pervasive. When people in everyday life describe something as 'schizophrenic', they mean a "split into contrasting parts".

The last few decades have seen the development of classification systems, such as the International Classification of Diseases of the World Health Organization, and the Diagnostic and Statistical Manual originating in the USA. These systems have been effectively used for the diagnosis of schizophrenia worldwide. Several multinational studies have shown that but for minor cultural variations, schizophrenia is understood to be the same all over the world.

How common is schizophrenia?

Population studies of schizophrenia all over the world have shown a rate of occurrence of 0.1 to 0.4 per 1 000 population per year. It appears that the number of new cases of schizophrenia is largely similar across different regions and cultures.

Although the number of new cases occurring per year is similar worldwide, there is considerable variation in the total number of cases (i.e. new cases occurring each year plus the chronic cases) in the general population which ranges from 1 to 7.5 per 1000 population.

Number of cases in developing countries

Developing countries have a consistently lower number of cases of schizophrenia than developed countries. As the rate of occurrence of new cases of schizophrenia in the developed and developing worlds is similar, the difference in the total number of cases may be due to difficulties in locating cases, higher death rates or lower utilization of health services in developing countries. Also, a consistent finding is the better outcome of schizophrenia in developing countries, which may also explain the lower number of cases than in developed countries.

Urban/rural and ethnic differences

In Chennai, India, the frequency of occurrence of schizophrenia is higher in urban, impoverished slums than in non-slum areas. Higher figures have also been reported among ethnic minorities in western Europe, and in some immigrant groups. Although there is an ongoing debate over the assertion that the frequency of occurrence is

Some facts and figures

Some facts

WHO estimates that 40 per cent of the 200 million disabled in the world suffer from mental disorders. As per World Bank reports, mental disorders are among the ten leading causes of suffering of people worldwide.

decreasing in recent years, research data have not been able to prove this convincingly.

Gender differences

Research has consistently shown that women develop symptoms of schizophrenia at a later age. This finding has emerged from studies examining the age at initial onset of psychiatric symptoms, as well as first admission to hospital. Nearly 60 studies all over the world have reported that in women, the age of onset is 3-6 years later than that in men. But there are no consistent gender differences in the frequency of occurrence of the disease.

A number of studies have also shown that female patients have a better outcome than males.

Death rate

Schizophrenia patients have a higher death rate than the general population. Immediately after discharge from hospital they seem to be at increased risk of death. The possibility of suicide and other violent causes of death is high among patients of both genders. The natural causes of death include disorders of the cardiovascular and respiratory systems. Among the poor, the susceptibility to infections is greater.



Aporba Bhattacharya

Risk factors

Since the definitive causal factors for schizophrenia are yet to be identified, there are very few clear-cut and known risk factors which increase one's predisposition to the disease. One of the strongest seems to be the genetic factor. Although the contribution of the genetic factor is believed to be high, no model of genetic transmission or predisposing gene has been determined. The chances of a person developing the disorder are greater if one or both parents or sibling(s) suffer from the disease. At the same time, however, non-genetic factors also play a significant role, as evidenced by research studies which have shown that in the case of monozygotic twins sharing

identical genes, the chances of both of them getting schizophrenia are less than 50 per cent.

One in ten patients with schizophrenia has an affected family member. In general, the risk increases among close relatives of the person with schizophrenia. If one parent is affected, the chances of the child developing schizophrenia is about 5 per cent. While genetic contributions are important, they are by no means the only possible risk. Ongoing research is likely to show clearer directions in future.

The family environment and “expressed emotions” have been found to be associated with relapses, if not with the actual genesis of the disorder.

Migration to a new environment and culture, which may be hostile to a person, has been associated with increased risk of schizophrenia. Accordingly, it may safely be presumed that schizophrenics would normally not be willing or inclined to marry in order to avoid a new and uncertain environment. However, the consistent evidence of an association between an unmarried status and schizophrenia leads us to believe that a closer and personal relationship, such as the one obtaining in a marriage, could have a protective influence on schizophrenics.

A subject of increasing interest to researchers is the association between the presence of birth complications and the onset of schizophrenia. This is called the neurodevelopmental hypothesis of the origin of schizophrenia.

The “selection drift hypothesis” has been developed to explain the observation that schizophrenia is more common in the lower social classes. As a corollary to this observation, the hypothesis goes on to explain that those vulnerable to schizophrenia go down in social class and drift to poorer environments. This, however, has not been replicated in other studies.

Until the etiology of schizophrenia is established, clear-cut risk factors for development of the disease cannot be identified.

Schizophrenia in the countries of South-East Asia is a serious public health problem. The condition as such, causes serious distress and suffering, decreases the positive strengths of an individual and affects the quality of life. The direct and indirect burden placed on individuals and families at the physical, social and emotional spheres is significant. Further, the fear of stigma often makes persons with schizophrenia to conceal their illness and not to seek health care, leading to their seclusion and isolation. Urgent efforts are required to improve the situation in all the countries of the Region.

Course and outcome of schizophrenia

Outcome of cases of schizophrenia

- About 45 per cent recover after one or more episodes.
- About 20 per cent show constant symptoms and increasing disability.
- About 35 per cent display a mixed pattern, with varying degrees of improvement or deterioration.

The term ‘course’ refers to the pattern of progression of an illness over a period of time. The common types of courses are continuous illness, a relapsing course with increasing disability, and a single episode followed by complete improvement. Both short and long-term courses have been identified in relation to schizophrenia.

Violence

Studies indicate that people with schizophrenia are not excessively prone to violence, except patients with a past criminal record, history of associated substance abuse or alcohol dependence. More often, patients are withdrawn and prefer to be left alone. However, some patients, particularly during periods when they are hearing voices or imagining threatening gestures targeted towards them, may become violent. Friends and family are usually the target of this violence. Media often links mental illness and violence. However, it has been observed that many schizophrenics are not especially prone to violence. Media often uses terms such as ‘mentally ill’, ‘psychotic’, ‘lunatic’, ‘*pagal*’, ‘psychopathic’, while sensationalizing crime. This has resulted in the broad myth and perception that all persons with schizophrenia are dangerous.

Outcome

The outcome is the status of the individual at a point in time or at the end point. Depending on the length of time for which the patient is followed up, the outcome can vary from one point in time to another. For chronic illnesses such as schizophrenia, it is more relevant to study the outcome at the end of five or ten years.

In the earlier half of the twentieth century, it was believed that schizophrenia is a prolonged illness with poor long-term prognosis. However, with the introduction of modern medicines, better community care and increasing awareness about the illness, the outcome of schizophrenia has, indeed, changed for the better. This has been adequately borne out by several multicentric studies.

Schizophrenia: patients falling into selected categories of course and outcome variables

Course and outcome category	Developing countries(%)	Developed countries(%)
• Remitting course with full remission	62.8	36.8
• Continuous or episodic psychotic illness, without full remission	35.7	18.7
• In psychotic episodes 25% of follow-up period	18.4	18.7
• In psychotic episodes 76-100% of follow-up period	15.1	20.2
• In complete remission 0% of follow-up period	24.1	57.2
• In complete remission 76-100% of follow-up period	38.3	22.3
• No antipsychotic medication throughout follow-up period	5.9	2.5
• On antipsychotic medication 76-100% of follow-up period	15.9	60.8
• Never hospitalized	55.5	8.1
• Hospitalized for 76-100% of follow-up period	0.3	2.3
• Impaired social functioning throughout follow-up period	15.7	41.6
• Unimpaired social functioning for 76-100% of follow-up period	42.9	31.6

Source: Jablensky A., Satorius N, Emberg G, Anker M, Korten A, Cooper JE, Day R, Bertelsen A. Schizophrenia: manifestations, incidence and course in different cultures. A World Health Organization ten-country study. *Psychological Medicine. Monograph Supplement* 1992;20:1-97. (Reproduced with permission from Cambridge University Press)

Components of outcome

The outcome itself is usually not a unitary one, but has different dimensions. These are as follows.

- Clinical outcome - improvement/persistence/deterioration of symptoms and signs of the disorder, number of relapses, intellectual performance;
- Social functioning of the patient;
- Work performance - this includes work in paid jobs outside the home, housework, studying (if a student), and work in a sheltered environment;
- Quality of life - this is increasingly being recognized as an outcome dimension.

In one individual, there could be much heterogeneity and only a weak



Sayan Banerjee

A consistent and repeated finding of research studies is that patients with schizophrenia in developing countries have a better outcome than in developed countries

relationship between these outcome dimensions. Though patients may be clinically asymptomatic, their social functioning could be poor and they may be unable to hold a job. It is equally likely that persons suffering from hallucinations or delusions may still be able to keep their job. Hence, for the purpose of psychosocial intervention, it is essential to assess each of these dimensions and plan programmes accordingly.

Family attitudes, emotions, their expression, and the nature and style of communication, have all been associated with an increased rate of relapse in schizophrenia.

Although schizophrenic symptoms are exacerbated following childbirth, the exact relationship is uncertain.

Differences in outcome in developed and developing countries

A remarkable and consistent finding has been that in developing countries, schizophrenics have a better outcome. This was based on the fact that more patients in the developing world remained symptom-free for longer periods after the initial episode. This length of remission (symptom-free period) was unrelated to drug treatment since many in the developing world did not receive continuous treatment. Psychosocial factors, such as better family support, community tolerance, extended networks and more favourable job opportunities, have been postulated as the reasons for this observation. From several studies, it is known that short duration of initial episode, few episodes in the past, good adjustment patterns, being married, early diagnosis and initiation of treatment, acute onset, good social support networks and total compliance to medication are some factors favouring good prognosis in schizophrenia.

Prognostic factors

Of all the prognostic factors outlined above, one single factor amenable to correction and/or modification is proper treatment consisting of early identification, treatment with medicines, family education and psychosocial rehabilitation. Unfortunately, however,

health care facilities for such treatment are woefully inadequate in developing countries.

Factors indicating a better outcome in patients:

- Female gender
- Married status
- Early treatment
- Acute onset of illness
- Rural background and cohesive family
- Absence of negative symptoms
- Predominance of florid positive symptoms
- Short duration of first episode
- Few episodes of similar illness in the past
- Good premorbid personality and adjustment

Factors indicating a poor outcome in patients:

- Male gender
- Unmarried status
- Earlier age of onset of illness
- Delayed treatment
- Irregular treatment
- Gradual (insidious) onset of illness
- Lack of social support
- More negative symptoms
- Positive family history of schizophrenia or major psychoses
- Poor social and occupational functioning before the onset of the illness
- Large size of ventricles of the brain, presence of subtle neurological signs
- History of substance abuse or alcohol dependence
- Excessive criticism, hostility or over-involvement in the home and family atmosphere

A true story

Gajraj is a young man of 25 living in Chansa, a village 50 km from New Delhi, India. Some months ago, he started hearing 'voices' which began to control his behaviour. His family members and neighbours thought he had "gone mad". They took him to a faith healer who gave him large doses of laxatives to purge out evil spirits from his body. Gajraj was almost on his death bed. Somehow, Gajraj's father felt something was not right and took him to the community health centre 15 km away. The doctor at the health centre first gave Gajraj intravenous fluids to replace what had been lost due to laxatives. After taking a history, the doctor diagnosed Gajraj's condition as schizophrenia. He spent almost one hour explaining to the family about the disease, about the need for medication and that Gajraj could benefit from treatment. He also advised that Gajraj should continue to perform routine agricultural work under supervision. He even offered to send his field health worker for periodic follow-up. Gajraj is now well adjusted, lives happily with his family and works in the field. He takes his medications daily.

- As reported by Gajraj's father

A disabling disease

Some facts

- India has about 5-6 million people who are chronically disabled by severe forms of mental illness. All of them require active rehabilitation, apart from medication. The scenario in other Member Countries of the Region is similar.
- The mentally disabled are the largest beneficiaries of the social security system in the USA.

Schizophrenia, like other chronic mental illnesses, has been recognized the world over as one of the conditions that causes major disabilities in several spheres of a person's functioning. These include self-care, activities of daily living, communication and work-related activities.

What is mental disability?

One of the definitions of disability often used is: "The inability to engage in any substantial, gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or has lasted or can be expected to last for a continuous period of not less than 12 months."

The United Nations has been more explicit in its definition of disability. According to the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the term disability "summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature."

Despite this emphatic inclusion of mental disability, many countries in the Region have not yet begun giving mental disability the attention it deserves.

Major areas of disability

Mental disorders produce disability mainly in the following areas of a person's functioning:

- Activities of daily living, including self-care - grooming, dressing, bathing, keeping one's body and the environment clean and looking after one's health;
- Social relationships, including communication skills, ability to form relationships and sustain them, social skills required for daily activities, and taking care of others, and
- Occupational functioning - the ability to acquire a job and hold it, the cognitive and social skills required for a job, doing housework, or studying if a student.

The third area of functioning is important, since it affects the livelihood of people suffering from this illness, especially those between the ages of 25 and 45. Unable as they are to hold a job, their families face untold suffering and carry a heavy burden.

Disability policy

The West has recognized mental disability for many decades now, but the developing world has yet to do so.

India: The Persons with Disability Act (1995) recognized, for the first time, disability caused by mental illness and placed it on par with other disabilities. However, before this could be translated into action at the state level, an Amendment Committee was formed to look into several issues, including the justification for inclusion of mental disability. The report of this Committee has been submitted to the Ministry of Health and Family Welfare and its outcome is awaited.

Sri Lanka: In the Parliamentary Act 28 of 1996, entitled “Protection of Rights of Persons with Disabilities”, a person with disability has been defined as “any person who, as a result of any deficiency in his/her physical or mental capabilities, whether congenital or not, is unable by himself/herself to ensure for himself/herself, wholly or partly, the necessities of life”. According to this definition, any disability associated with a mental disorder is recognized as a disability for the purposes of the Act.

Thailand: Policies on disability due to schizophrenia are at par with other disabilities.

The problem of disability is an important one in Thailand: there were over a million disabled persons in 1991 with the number being much larger now. Schizophrenia is one of the major problems. Therefore, the government has made



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Shwe War Phone

policies such as the Rehabilitation Act of 1991, for supporting the physically as well as the mentally disabled persons.

These disabilities include:

- Visual disabilities;
- Hearing or language disabilities;
- Physical or movement disabilities;
- Mental or behavioural disabilities (including schizophrenia), and
- Intellectual or learning disabilities.

The disabled must be registered to be eligible for protection, support and welfare. Services provided include:

- Medical services (diagnosis, investigation, medication, surgery and counselling);
- Developmental services (education, job training, social welfare and social participation);
- Rehabilitation (physical and psychiatric rehabilitation and hearing aids), and
- Miscellaneous services (e.g. financial help for various purposes, such as short-course training).

Fighting against discrimination

One of the reasons for the developing world's reluctance to recognize mental disability could be the lack of awareness of this cause of disability: it has a rather subtle and hidden nature compared to the more obvious forms of disability, such as paralysis of the limbs and visual disabilities. The lack of awareness and sensitivity about this issue, even among mental health professionals, seems to be working against the mentally disabled. Compounding this is the lack of strong lobbying groups. This partly arises from the fact that unlike other groups of disabled, the mentally ill cannot and sometimes do not speak up for themselves, due as much to the effect of the illness or their inability to express themselves as to the stigma of having a mental disorder. Support groups could advocate the cause of patients with schizophrenia, helping to create awareness, and dispel myths and misconceptions about schizophrenia among community members to remove stigma.

Fighting discrimination, removing stigma

Discrimination and stigma are major problems faced by patients with schizophrenia. ALL have a role to play in fighting discrimination and removing stigma.

Unlike some infectious illnesses or genetically-transmitted disorders, it is not possible to prevent the development of schizophrenia. Although it is possible to identify high-risk populations, such as children born to parents with the disorder, no intervention has been discovered as yet to delay or prevent its manifestation. It is possible that the increase in genetic research will result in the development of some prevention strategies in future. It is also possible that the prevention or reduction of obstetric complications, by ensuring safe pregnancies and deliveries, could reduce the risk of schizophrenia.

The goals of care are to identify the illness as early as possible, treat the symptoms, provide skills to the family, maintain improvement over a period of time, prevent relapses and reintegrate the ill person in the community to lead a normal life.

Early diagnosis

For this, it is critical to increase the level of awareness about the illness since many of the early symptoms can be similar to those of several other conditions, such as depression. Hence community awareness and education need to be promoted on a large scale.

Training of primary health care personnel and grassroots-level workers

There are very few psychiatrists and other mental health professionals relative to the population in most countries of the Region. Thus, vast segments of the population, particularly rural communities, are deprived of even basic mental health services. Many governments have launched programmes to integrate mental health services into the existing primary health care delivery system. This can ensure, to an extent, more effective case detection, appropriate referrals, follow-up and rehabilitation of patients within the community.

Involvement of the community, and nongovernmental and private agencies

Such involvement would be of great help in identifying, treating and supporting schizophrenics. Specific activities in

which the community can be involved include setting up day care centres and sheltered homes for patients; providing supervised employment opportunities for patients within the community so that the patients remain in a familiar environment; providing social support to the family and, most importantly, helping remove stigma about the illness.

Reduction of disability, promotion of the patient's assets and empowering the patient can be achieved through effective psychosocial rehabilitation measures.

Medical management/treatment

The treatment for schizophrenia has three main components. Firstly, there are medications to relieve symptoms and prevent relapse. Secondly, education and psychosocial interventions help patients and families cope with the illness and its complications, and help prevent relapses. Thirdly, rehabilitation helps patients reintegrate into the community and regain educational or occupational functioning.

Once diagnosed, the condition needs to be treated. In many countries of the Region, facilities for treating psychotic disorders are meagre and concentrated in urban areas. It is essential to increase the availability and accessibility of mental health services to deliver care and



Vaishavi Sachin Ambre

treatment. The integration of mental health into primary health care, which has been advocated in countries, such as India, for several decades, may be an effective way to tackle this lack of adequate facilities.

Medical treatment is the most important component of intervention and must be adhered to strictly if the patient is to show consistent improvement. The antipsychotic drugs prescribed aim at controlling the acute symptoms of the illness, suppressing distortions in perception and thinking, and also ameliorating some chronic symptoms, such as apathy and social withdrawal. Although medications do have some side-effects, their beneficial effects far outweigh the adverse effects. Patients are strongly encouraged to take these medications as prescribed. Occasionally, ECT (electroconvulsive therapy or shock treatment) is advised during an acute phase of schizophrenia, but usually in conjunction with drugs.

Some important components of psychosocial rehabilitation programmes

- Social skills training
- Group therapy
- Cognitive training
- Work training or vocational rehabilitation
- Use of dance, music and yoga therapy

How important is medication?

Medications are vital because they help in restoring the normal functioning of the brain. Once the illness has been identified and the patient starts on a programme of drug treatment, it is vital that the treatment is adhered to. These drugs are the product of years of research and have a definite beneficial effect. If they are stopped for any length of time, the disease will inevitably progress on its course of relapses and deterioration. Until recovery has been effected, the drugs should not be stopped. Sometimes, treatment with drugs has to be continued for a long period, beyond the point of recovery, to prevent relapses or deterioration.

Nature of medication

The most commonly used drugs in the treatment of schizophrenia are known as antipsychotics or neuroleptics. These act on the brain. Conventional or typical neuroleptics are those that have been in use for several decades. Unconventional or novel antipsychotics have been recently introduced and their mechanism of action is different from that of conventional drugs.

Typical/Conventional antipsychotics

These include phenothiazines, butyrophenones and thioxanthenes which act by blocking a particular kind of receptor in the brain called the D2 receptor. There is reliable evidence that in the acute phase of the illness, these drugs are effective in controlling the positive symptoms (delusions, hallucinations and thought disorder). About 60-75 per cent of patients improve in 6-12 weeks.

The common drugs used extensively even now in many developing countries are chlorpromazine (first discovered in 1952), haloperidol, thioridazine and trifluoperazine. These form the mainstay of treatment, especially in rural areas, where access to medication is much less than that in urban areas. The problem with this group of drugs is that they have both short and long-term side-effects which could range from the mildly unpleasant to the potentially debilitating. Despite side-effects, the low cost, availability and years of experience in using these drugs make them still suitable for developing countries.

Depot injections

Antipsychotics can be taken orally, in the form of a syrup or tablet. Some are also available as injections. Depot injections are slow-release forms of antipsychotics, administered about once every six weeks. Because of the convenient dosage schedule, many patients comply better with depot injections than tablets, but the side-effects experienced with the former are often worse. Atypical drugs are not available as depot injections.

Atypical/Unconventional antipsychotics

These are indicated for patients who do not respond to conventional antipsychotic drugs. The primary advantages of atypical antipsychotics are their effectiveness in dealing with the negative symptoms (such as apathy, social withdrawal and blunted emotions) and some behavioural problems, as well as the relatively lower occurrence of side-effects. Their high cost, however, limits their use in most developing countries.

Psychosocial interventions

Psychosocial intervention in schizophrenia has gained an important position in the total management of the disease.

Psychotherapy, in conjunction with other measures, is often helpful. These techniques use behavioural modification, contingency management, coaching, modelling and over correction. In addition, group therapy, vocational training, social skills training and leisure management skills are also imparted to these patients.

Psychosocial rehabilitation is defined as an overall strategy that encompasses not only health services, but also legislation, social policy and economics. It is basically a set of techniques aimed at reducing symptoms and decrease the impact of illness, improve skills and capability of the person and increases family support in day-to-day management and disabilities. Recently, there has been tremendous progress in rehabilitation measures all over the world. Nongovernmental organizations have been in the forefront in this effort and researchers, too, have evinced interest in this discipline which often lacks empirical data. International organizations have been formed to facilitate the process in many developing nations.

Involving a person with schizophrenia in appropriate activity can help by...

- Contributing to family income
- Diverting the mind of the person
- Increasing self esteem
- Reducing stigma
- Bringing an order to life
- Improving interaction with people
- Integrating the person into society

Psychotherapy

Very often, the severe loss of self-esteem and depression suffered by patients can be countered only by effective psychotherapy. This consists of sessions of counselling and encouragement, and extension of positive support to the patients by friends and family. The patients talk on a regular basis with a mental health professional, such as a psychiatrist, psychologist or case manager. This helps them to freely express their perceptions, problems and experiences. Sympathetic counselling enables them to learn to distinguish the real from the unreal and the distorted, and to gradually gain a better understanding of their illness. Very often, they learn to live with symptoms which cannot be completely eliminated.

Social skills training

Antipsychotic medication and social skills training can be mutually reinforcing. Patients can be taught to identify their symptoms early and to prevent a relapse. Very often, a checklist is provided both to the family and the patient to help them recognize and report early warning signs. Those who do not have periods of remission learn to keep

persistent symptoms from interfering too much with their daily lives. Patients can also be shown how to reduce stress by leading a more healthy life, such as by not taking alcohol or drugs.

Training is also provided in daily activities such as bathing, cleaning, cooking, using the telephone, using modes of transport and making basic financial transactions. Affiliative skills such as making friends, engaging in conversation and communicating with family and friends are also key elements of such programmes.

Housing is not a big problem in many developing countries, since most patients live with their families. However, estrangement of the mentally ill from nuclear families and consequent homelessness are on the rise.

Procedures for social skills training must be tailored to the needs of individual patients as they present different combinations of social abilities and deficiencies and have varying degrees of support from their environment.

Work and occupation

Most developing countries do not have a social security system for the mentally disabled, unemployed persons. In these countries, it is of paramount importance to focus on providing these persons with employment and work. The patient's family perceives disability in work functioning as the most burdensome problem. Hence, most rehabilitation programmes lay great stress on this aspect.

First the person with schizophrenia has to be motivated to start thinking of work by encouragement to apply for jobs, to follow this up and to be alert to any possible openings. Before this, it is essential to determine what kind of job the patient is most suited for. This can be done by an assessment of skills and disabilities, and is often a combined decision of the patient, the family and the rehabilitation team.

Case managers must then identify suitable jobs, meet the employers and brief them on the patients and their capacities, and also muster employers' support. Periodic liaising with the employer and close monitoring of the

patients at their workplace are often required. Getting a mentally ill person to stay on in a job is one of the most daunting challenges of rehabilitation.

Work in sheltered settings, which facilitates the establishment of a work culture and daily schedule, can be a useful prelude to employment. Some severely disabled patients will need to work in sheltered conditions all their lives.

It is also the responsibility of the rehabilitation team to prepare the ground before placing a mentally-ill person in a workplace. The employer, colleagues, patients and their families have to be oriented on the various problems which may arise at work, and should be equipped with the necessary skills to manage these.

Development of intellectual skills

It is well known that schizophrenia can lead to shortcomings in intellectual functioning, such as lapses in attention, concentration, concept formation, reasoning and problem-solving. These shortcomings not only interfere with daily activities, but can also affect the patient's intellectual performance at the workplace. An extensive assessment of the patient's intellectual functions is important in formulating a rehabilitation plan. Computerized and verbal interactive programmes can then be used to gradually improve the shortcomings.

Various settings of rehabilitation

Regarding service delivery mechanisms, significant developments have taken place over the past two decades. These are development of half-way homes and other measures like day-care centres by nongovernmental agencies for rehabilitation services. These are developed in keeping with the local sociocultural context in different countries. These facilities vary in terms of intake criteria of patients, philosophy and management techniques. Depending on the



Preeti Snigdha Nayak

location of the patients, their access to services and the resources available to the family, rehabilitation can be carried out in different settings. These are as follows:

Day-care

This is more suitable for urban populations. Day-care facilities are run by governmental and NGO sectors. These are facilities where patients spend a part of their working hours and are trained in vocational activities, development of work cultures and behaviour. Patients spend a greater part of the day at the centre where they are exposed to a rubric of intervention strategies. They could also be trained in some kind of work. Apart from introducing a schedule in the patients' lives, it also gives the families some respite and reduces their burden to an extent. Most of the facilities assist patients to get employment. It has been found feasible to employ patients in supervised jobs after a period of training. Day-care centres also ensure drug compliance, provide relief for the family and discipline for individuals.

The experience of different models of day care in government and nongovernmental sectors has been promising as they are based on low cost, with family involvement and people's participation. These models are replicable and can be managed by family members or trained volunteers.

Residential rehabilitation

At times, a short stay at a rehabilitation facility is necessary. Some likely factors for this requirement are relapse, non-compliance with medication or disturbed interpersonal relationships with family members, especially those characterized by hostility. Sometimes, the family may need a place for the patient to stay for a short duration while they are engaged in some special activities such as a marriage or a function.

Home-based rehabilitation

This is necessary in the case of patients who are confined to their homes and are unwilling to move out.

Community-based rehabilitation

It has been widely recognized that in the face of limited manpower and fiscal resources, community-based rehabilitation is the most satisfactory strategy for dealing

with chronic disabilities, including mental illness. While community-based rehabilitation (CBR) may be initiated and established by mental health professionals, this programme should be run with minimal professional inputs and maximal community involvement and participation. Some institutions in the country have instituted CBR programmes which is a promising strategy in the long run.

The overall result of such a comprehensive approach is that patients not only improve as a result of medication, but also recover their self-esteem and become more confident of their place in society as they gain proficiency in some trade and continue their counselling sessions. Reintegration into society is the ultimate goal of all rehabilitation.



Aindrila Dey

What can be done?

What the family can do

In almost all developing countries, over 95 per cent of the chronic mentally ill live with their families. Since persons with schizophrenia are often limited in their capability to interact, get employed and lead a normal life, family members have an extremely important role to play. Providing adequate knowledge about the illness, involving them in therapy issues and helping them to develop support mechanisms go a long way in reducing burden and improving the quality of life of the patient.

The family often finds itself in the unenviable position of being criticized by other family members and friends. The physical and emotional efforts involved in looking after the patient can be both rewarding and burdensome. Hence, families need considerable inputs and support from professionals to help them manage the patient as well as their own lives. The following are a few suggestions on what the family can do.

Ensure compliance with treatment

A number of patients are unwilling to take medication. This may be because they feel well, or do not have any insight into their illness, or because of the distressing side-effects of the medicines themselves. The family, however, has to make sure that the drugs are taken in the prescribed dosage. Some patients keep the tablets in their mouths and spit them out later. It has to be ensured that the tablets are swallowed. At the same time, a watch must be kept on the possibility of overdose. Depot injections, which are effective for a long period, can be given. Working closely with the members of a rehabilitation team also helps.

Seek help and support

Family support and solidarity are vital. Bonds may be based on spiritual strength, creativity and closeness with other family members (grandparents, aunts and uncles). The feeling of being linked by such bonds is highly desirable. Friends and neighbours can also be of help.

The process of caring on a day-to-day basis may warrant a lot of help from other sources as well. Do not hesitate to take help. Assistance may be required from several sources.

For example, the police will have to be contacted if violence or crime is involved; the therapist may be needed after the immediate crisis has been controlled. The therapist must also be contacted if there are signs of relapse, or refusal to take medication for a few days. The ways in which the police can be of help is usually clearly outlined in the Mental Health Act of a country or its states.

Take an interest

As part of the treatment programme, family members should talk to the patients and show an interest in what they are doing, even if they sound dull and repetitive.

Assign small responsibilities

It is important for schizophrenics to master simple routines first. Performing simple tasks around the house helps boost their sense of worth as they improve. These tasks should be simple and uncomplicated, and the patients should not be pushed, as “overloading” will only tire and confuse them.



Machi Pelha

Many families feel that the patients have changed so much that they seem like total strangers

They should be made to feel that they are as valuable and productive as any other member of the family.

Supervise

The need for supervision varies. Patients who are chronically ill or who express suicidal thoughts and seem very depressed, need constant supervision. Those undergoing treatment must be supervised periodically in order to ensure that they take their medicines, maintain personal hygiene and do not relapse. As the patients improve, they become self-sufficient and safely function alone, and the need for supervision will slowly decrease.

Encourage and support the patient

It is important for a family member to let the patients know that they have a future, far as it may be from what was originally envisaged. Schizophrenics are very vulnerable - they desperately need assurance about their worth, are very sensitive and need people to believe in them.

Accept the changes

After an episode of schizophrenia, it is often hard for patients to talk. Getting through to persons who cannot or will not talk is frustrating, but it must be remembered that they are not being mean, stubborn, defiant or tight-lipped. They are having a hard time trying to decide what has happened to them and it is not easy to put this kind of confusion into words. Family members should try to understand their gestures and facial expressions, and speak to them directly and in a supportive way, in clear, short and simple sentences. Patients must be allowed time to find their answers. The family should be prepared to listen patiently for fairly long periods of time even if what the patients say does not make complete sense.

Avoid over-involvement

The family can display a wide array of emotions, ranging from overprotection and over-involvement to hostility and rejection. It is generally advisable to keep one's emotions in low key. One should not shy away from contradicting or disagreeing with the ill relative. Feelings must be expressed in a matter-of-fact way rather than angrily.

Many family members, particularly parents, practically start

leading the patient's life, make all his/her decisions and do not encourage independent thinking. Apart from stifling the patient, this may also lead to resentment, with the patient interpreting interest and support as interference and 'meddling'. In such a case, it is better to back off and stand by in case of need, rather than involve oneself actively. But the patient should not be ignored altogether. It is important to strike the right balance between caring involvement and constant intrusion.

Appreciate

Appreciation of the smallest task is important. Unless the patients' abilities and efforts are recognized and appreciated, their self-confidence will remain extremely low. As far as possible, ignore deluded or abnormal talk. Appear interested, and try to prolong normal talk and conversation.

Do not ignore

Ignoring the patients tends to destroy their self-esteem. Even their smallest achievements must be appreciated. Their desire to talk or discuss their future should be taken up sympathetically. Family members should be patient and supportive.

Do not criticize

Derogatory statements, criticism, or taunting behaviour can have a very traumatic effect on the patients, who are in a very sensitive state and easily hurt. Harassing them only adds to the stress and may result in the return of acute symptoms.

Respect their intelligence and capacity

The patients' intelligence should not be undermined. Distortions in thought and perception apart, they are still aware and sensitive individuals. Insensitive discussions in their presence on their condition or future could prove to be very harmful. They are capable of many activities. It is important to determine what they are capable of and to encourage them to do that.

Watch for a relapse

Often, relapse occurs for no obvious reason. Family members should watch out for early signs of relapse, such

Remember...

While many families do far more than expected (e.g. they listen, advise, encourage, support, entertain, nurse, and facilitate living and working), they need to set certain limits. Otherwise, they may fall into the habit of continually overextending themselves, thinking that if they give even more love and care, the patient will get better. While the importance of care and love cannot be overstressed, it must not be seen as a miraculous cure-all. The end result of nurturing unrealistic hopes is that they are often dashed sooner or later, leaving the helper angry, disappointed and frustrated, or at times, hopeless and deeply depressed. Expecting too much of oneself, in addition to being unrealistic, actually makes the task of helping the patient more difficult.

as sleeplessness, increased restlessness, irritability and a return of hallucinations. The patient should be taken to a psychiatrist immediately so that medication may be adjusted and a relapse prevented.

Maintain a check

Even after patients are rehabilitated and go back to work or study, it is important to check on their progress regularly in order to prevent a sudden, unforeseen relapse. If they go to work in another city, it must be ensured that they are in touch with someone there - a friend or relative - who can give periodic reports of their progress to the family.

General health and nutrition

A diet rich in proteins, vegetables and milk, with some roughage, that is, green vegetables and fruits should be given. Large quantities of carbohydrates (rice, potatoes), fat (oily food, cheese, fast foods), and stimulants (coffee, cola drinks) should be discouraged. The patients must be coaxed to eat with their families, but one should not be angry if they refuse. If they do not eat properly, vitamin



Dhruv Suri

supplements should be provided. The family doctor should be notified if three or four days go by without proper meals. Patients may display odd tastes in food (such as eating raw rice), which may be detrimental to their health. This must be dealt with gently but firmly.

Patients must be encouraged to become responsible for their own hygiene but they should be lent a hand occasionally, such as while bathing. To start with, a change of clothes can be kept ready for them and eventually, they will get the idea and start doing it themselves. Laundry and keeping the room clean is part of hygiene.

Exercise in some form should be encouraged, although patients may resent this. They prefer to stay in bed or sit still for hours. One must try to get the patients interested in walks in the park or go to the market, and in sports. Some patients respond if they are accompanied, as doing things alone is initially frightening for them. A variety of hobbies should be encouraged, but one should not be disheartened if nothing catches the patient's interest immediately.

The use of unprescribed drugs, marijuana, tobacco and alcohol is undesirable. This must be made clear. Patients should have periodic check-ups, like everyone else. The family doctor should know what medications the patients are on, as these may cause some side-effects, such as constipation, blurred vision and dry mouth. The dentist should also be consulted periodically.

Look after yourself

There is no need to be a martyr - such an attitude will adversely affect one's ability to look after the patient effectively. The support of other relatives and community support staff should be enlisted. Family members should involve themselves in interesting activities so that they are not overly preoccupied with the ill relative. One must continue taking holidays, pursuing one's interests and socializing. The patient will probably fare better if the family members do less rather than too much.

Reducing stigma

The stigma associated with schizophrenia and other mental disorders has existed for centuries, beginning with the use of the term, 'lunacy'. This stigma affects the individuals with illness for almost their entire life. No one involves them in work, at home, play or at social functions. They are ridiculed and made the object of jokes and called by a variety of names by people around them. A large number of misconceptions (mentioned earlier) contribute to this phenomenon.

The effect of stigma on a person with schizophrenia results in non-availability of substantial help (medicines, job, income), social isolation and neglect. This worsens the situation and results in the many negative effects. How people perceive this illness is influenced by cultural belief, social influences and family bonding. Removal of stigma is the responsibility of everyone. Acceptance of the right of schizophrenics to live with dignity and continuous support are crucial. Changing perceptions is a difficult task, but it can be achieved by increasing awareness and recognition at all levels.

Unlike many physical illnesses, schizophrenia is a disorder which has not just clinical, but family and social ramifications as well. The recovery, rehabilitation and reintegration of a patient cannot be accomplished without community support.

Role of families of the mentally disabled

Since those disabled by schizophrenia may not make effective spokespersons for their cause, it is absolutely crucial for families to organize themselves into pressure groups to advocate the welfare of the mentally ill. NGO initiatives in psychiatric disability intervention is not on par with that of other disabilities. This is a promising area and countries in this Region can benefit from these locally relevant and economical approaches. This sector is growing slowly and steadily and may become a major source of care for the mentally ill. Further, this also helps in reducing the stigma of mental illness by shifting the care from custodial care to community care with people's participation. A small beginning has been made in India, Sri Lanka and a few other countries, but there is a long way to go. Unless this is done, policy planners will continue to ignore this disability, thereby depriving some of the most disabled of certain basic facilities.

Finally, there are support groups emerging in the Region. These include families of patients who can offer different kinds of help. It is advisable to become a member of a support group in one's city or town, or even help start one. Emergence of family groups are in the form of self-help groups or advocacy groups. These groups can set up rehabilitation facilities. Government initiatives like the Persons with Disabilities Act 1995 of India encourages family associations to start programmes.

What the community can do

Unlike many physical illnesses, schizophrenia is a disorder which has not just clinical, but family and social ramifications as well. The recovery, rehabilitation and reintegration of a patient cannot be accomplished without community support. Hostility, abuse, rejection and stigmatization by the community can impede progress and even result in a relapse or increased disability. Hence, the role of each of us as members of the community at large is vital.

Members of the community can do the following to help patients and their families:

- First, schizophrenia must be recognized and accepted as a disorder of the brain, just like stroke or epilepsy.

The Community can make a difference...

The Schizophrenia Research Foundation, better known as SCARF, is an NGO in Chennai, India. For the last 15 years, SCARF has been offering community-based services in both urban and rural areas at Thiruporur, about 50 km from Chennai. The entire catchment population of nearly 1 lakh was screened for mental illness with the help of local residents, primarily young women. The services provided consist of outpatient care, residential rehabilitation services, family support and education, liaising with community institutions such as schools, temples and churches, and even sponsoring the education of the children of those who are too disabled to work. SCARF has also been able to forge research links with reputed national and international centres, and has been recognized by WHO as a Collaborating Centre for Mental Health Research and Training. The experience of the last 15 years has clearly shown that rehabilitation has to be tailored to the individuals, according to their personal needs and that of their families.

The Richmond Fellowship Society (RFS) of India, an affiliate of RF International, UK, is a registered society working for making a difference in the quality of life of persons with mental illness. It has established therapeutic community programmes for the last 15 years. It runs half-way homes, group homes and day-care centres with regular training facilities. RFS has branches in Bangalore and New Delhi in India, Nepal, Thailand and Sri Lanka. The Centre offers counselling, management and psychosocial rehabilitation for persons with mental disabilities. The Fellowship is a founder member of Richmond Fellowship, Asia-Pacific Region, working for exchange of information, organizing scientific meetings, staff exchange programmes and increasing public awareness.

The National Institute of Mental Health and Neurosciences, Bangalore, India, has been running community-based programmes around Bangalore, besides imparting training to primary care physicians in the area. A number of training manuals have also been published by them.

Therefore, patients are not responsible for their behaviour and should not be blamed for it, however bizarre and distressing it may be.

- An attempt must be made to explore the local community to identify any resources that could help such people.
- Community members should talk about the illness and its disabilities. Information emanating from people who are in no way associated with the sufferers facilitates acceptance of the patients better than information given by families or professionals. This will also help reduce and remove the stigma attached to the illness.
- Local awareness programmes should be organized. In India, leprosy was stigmatized for centuries, but the spread of correct scientific information on the illness and nationwide campaigns have reduced the stigma considerably. Leprosy is now viewed as a curable

medical condition. An alliance can be formed with family and patient groups in the area to work on common interests. If there are none, it would help to start one.

- Community members should become spokespersons for the mentally ill and liaise with community organizations, educational institutions, religious leaders and local companies.
- If there are care-providing centres in the area, those considered to be in need of help should be referred to these centres. Several studies have shown that the mentally ill and their families are not aware of existing facilities, and this results in underutilization.
- A very important role that can be played by community volunteers is to help place the patients in some jobs. Many potential employers, through careful dialogue, can be convinced to employ schizophrenics who have partially recovered. Being outside the formal mental health network, they are eminently suited for this role. Once the employers have been convinced, mental health professionals can step in to identify suitable persons for the jobs.
- Those with writing skills can write simple, non-technical articles on schizophrenia for the local newspapers and magazines. Patients and their families should be encouraged to write firsthand accounts, ensuring anonymity if desired.
- Insurance companies must be educated about the need to cover schizophrenia in the same way as other brain disorders.
- Vigilance must be maintained about any violation of human rights of these individuals by various sections of society.
- Local advertising campaigns should be organized to combat stigma. For example, local grocery stores can be convinced to carry informative messages on their grocery bags, such as “Schizophrenia is a brain disorder. People with schizophrenia are not responsible for their abnormal behaviour and need to be treated.”
- Community volunteers could help bring out booklets on the illness, the facilities available in the neighbourhood and the laws pertaining to the mentally ill.

In short, identification with the mentally ill and their families, sensitivity to their needs and mobilization of resources is necessary to improve the quality of their lives.

What medical professionals can do

The help that medical professionals can provide varies greatly from one country to another. Till recently, schizophrenics were looked after mostly in mental hospitals and large institutions. In almost all the countries of the region, the maximum number of hospital beds for the mentally ill are occupied by chronic schizophrenic patients; some of them for over 50 years. While such a situation has numerous ill-effects, there were hardly any alternatives for these people.

It is becoming increasingly obvious that care for schizophrenics will have to be delivered in less restrictive settings, which are also less stigmatized. Long-term institutionalization should be avoided, as far as possible, although in the absence of necessary social support, it does seem inevitable in some cases.

Gap in service delivery

Do countries in the Region have adequate facilities to deal with the schizophrenic population? The answer is no. In many countries, the number of trained mental health professionals is totally inadequate to deal with the medical and social ramifications of the illness. Also, these professionals are concentrated primarily in urban areas. Mental health services in rural areas are scarce. In order to meet this challenge, many countries have identified the integration of mental health services with primary health care as the most feasible solution. These need to be expanded.

To a very small extent, the gap has been filled by NGOs, but their numbers have to multiply consistently if they are to make an impact in their respective countries.

Traditional and religious healing

It is well-known that a majority of the mentally ill, especially in rural areas, first seek the help of traditional and religious

healers in mosques, temples and churches. The healing methods range from simple, daily rituals and prayer to physical methods aimed at restraining the patient, such as chaining or tying to a tree and depriving the patient of food. Some methods are very dangerous and harmful. Some effort should be made to educate such practitioners about the reality of mental health issues.

Data from Bangladesh reveal that before coming to the Pabna Mental Hospital Outpatient Department, up to 9 per cent of patients have been completely untreated, 21 per cent have been to a traditional healer and up to 46 per cent of patients have been to a GP and traditional healer. These data clearly indicate the importance of faith-healers for the community.

What NGOs can do

The last few decades have witnessed the establishment and growth of community-based programmes. Most of these are run by nongovernmental organizations and some by private medical professionals. Apart from acute care, these centres offer rehabilitation and awareness programmes at various levels.

What governments can do

Some countries in the Region have developed a national mental health policy, while others are in the process of doing so. Progressive policies will go a long way in helping patients with mental illness to integrate into society and also in the optimum utilization of mental health facilities. The policy of de-institutionalization, i.e. developing programmes which will enable patients to be discharged from chronic care facilities and yet be provided mental health services in the community, needs to be developed and promoted. Sri Lanka has already implemented such programmes successfully. Community-based mental health programmes integrating such services into existing primary health care programmes should be considered. Welfare and rehabilitation services play a major role in assisting patients in integrating into the community and their families, and in helping them to work gainfully. Models for such programmes are available in some countries and should be expanded.

The vital role of NGOs

'SAHANAYA', a community mental health centre, was established in 1983 by the National Council for Mental Health in Colombo, Sri Lanka. The organization provides a range of community-based mental health services by professionals and volunteers. Initial and follow-up assessments are done in detail with special reference to psychiatric, psychological, social and other needs before deciding on a plan of action. A whole range of daily living, social, occupational, personal care, recreational and vocational skills is offered to those suffering from disabilities associated with schizophrenia. Activities include gardening, dancing, art, music, envelope-making, shopping and cleaning. About 35 people attend the programme daily. SAHANAYA staff provide a home-based skills development programme in special situations when patients with disabilities associated with schizophrenia are not able to attend the centre. Education and training programmes related to rehabilitation are offered on a regular basis to a range of mental and health professionals working in the community. Several advocacy activities are also carried out with special reference to those suffering from schizophrenia. These include newspaper articles, public seminars, radio and TV programmes. Counselling both individual and family, psychotherapy and other forms of psychosocial interventions are offered to individuals.

AMEND - Association for Mentally Disabled - is the first and only self-help group in India started by a consumer (patient) for families of persons suffering from psychiatric problems. Since its inception in 1992, it has serviced more than 500 families in Bangalore, where it is located, and in the rest of India as well. The major components of self-help are awareness/education, training, family support through meetings, and, finally, advocacy. AMEND is the first group to pioneer a structured family education and training programme. Similarly, it is the first to initiate a patients daily living skills programme as well. The fundamental motto is family and consumer empowerment.


The RFS(I) at Bangalore, with its experience of nearly 15 years in the area of psychosocial rehabilitation, offers a two-year M.Sc. Course in psychosocial rehabilitation. This college, affiliated to the Rajiv Gandhi University of Health Sciences, is recognized by the Rehabilitation Council of India and is located at Bangalore.

The World Association for, Psychosocial Rehabilitation in association with governmental and nongovernmental agencies, has been undertaking sensitization and awareness programmes among mental health professionals, families and interested public. This is being done to promote people's involvement in psychosocial rehabilitation of persons with schizophrenia. These programmes eventually help in developing care facilities in respective regions for the chronic mentally ill.

Conclusion

Schizophrenia is the most common severe mental disorder, with an ubiquitous distribution all over the world. Schizophrenia has been written about and even explicitly described in ancient books of medicine. Worldwide, millions of dollars are spent on research on schizophrenia. Despite this, there are wide gaps in understanding this disease. Although it is widely accepted as a disorder of the brain, the exact pathology is yet to be determined.

However, the last few decades have witnessed the introduction of new drugs to treat this disorder. We also see a plethora of intervention strategies being implemented, the most recent one being cognitive therapy. Schizophrenia is also a greatly stigmatized condition. This can pose an immense burden to patients and their families, especially if the patient is a woman. Attitudes towards the mentally ill are archaic even in the most sophisticated societies. No attitudinal change can happen overnight. What is therefore needed is a well-systematized programme involving the government, NGOs, private practitioners, traditional healers, school teachers and all sections of society. Unless this is done, the mentally ill will continue to occupy the backyards of hospitals or their homes, shunned and ostracized by society.

A photograph of a sunset over a body of water. The sun is a bright yellow circle in the center of the frame, casting a shimmering reflection on the water's surface. The sky transitions from a deep orange near the horizon to a pale blue at the top. In the background, a dark silhouette of a city skyline is visible against the horizon. The water in the foreground is dark with small, choppy waves.

**Today
there is hope for persons
with schizophrenia
and their families**